MA Thesis

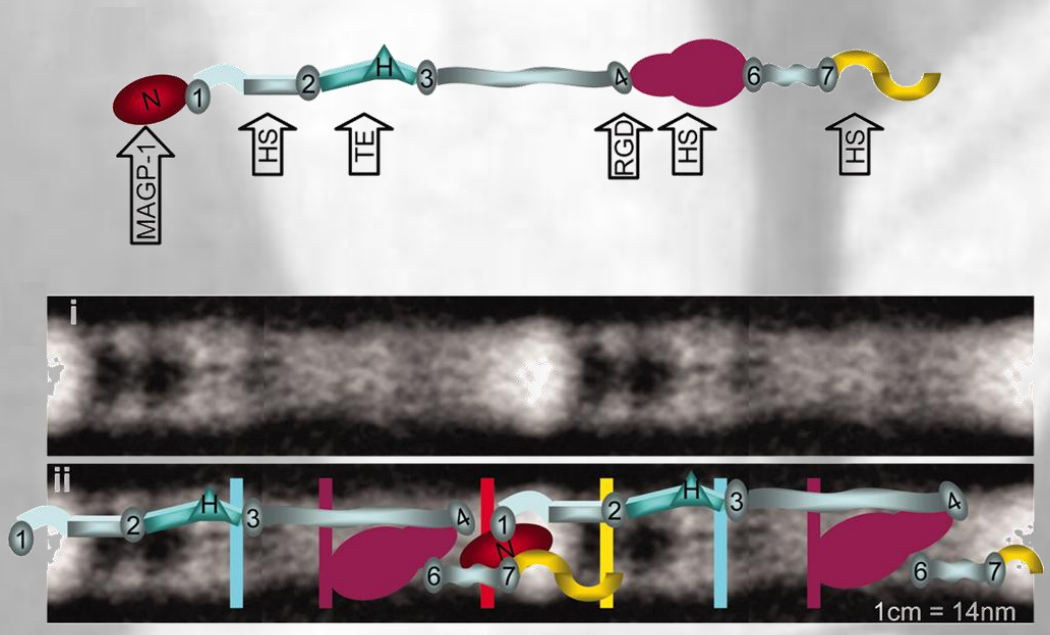
Utrecht University
May 2011

Jaap Slingerland
9852700

Supervised by
dr. C. Koster
dr. R.G.J.L. Supheert

Teens with Marfan

Translating Medical Texts for Young Patients



Cover images

The black-and-white photo on the cover background shows the hands of a Marfan patient. The coloured picture on the foreground shows an analysis of the fibrillin-1 gen. Mutations in this gen cause Marfan syndrome. Arachnodactyly or ‘spider fingers’ is one of the properties of Marfan.

The combination of these images represents the way specialised medical knowledge and the day-to-day effects of Marfan interlock in the lives of patients and their relatives. It also metaphorically refers to the presence of both extremes in medical texts for young patients, and the translation problems that this combination brings along.

‘A text is “functional” when it serves the function or functions it is intended for, and text function is determined by the factors of the situation in which the text will have to serve as as a communicative instrument (i.e. the time, place, and purpose of, and motive for reception, the medium by which it will be transmitted, and the audience it will be addressed to’.

Christiane Nord (1997:55)

‘ [We] need to distinguish between comprehension strategies and production strategies [...]. *Comprehension strategies* have to do with the analysis of the source text and the whole nature of the translation commission [...]. *Production strategies* [...] have to do with how the translator manipulates the linguistic material in order to produce an appropriate target text. I shall be concerned here with production strategies only. [...]
[The] kind of classification we can set up for production strategies must be a linguistic or text-linguistic one [...]. At its simplest, such a taxonomy might consist of a single strategy only:

Change something.’

Andrew Chesterman (1997:92)

[Table of Contents]

Chapter One
Introduction

1.1 | Marfan Syndrome: A Guide for Teens 8

1.2 | Research Question 9

1.3 | Method 9

Chapter Two
Theoretical Framework

2.1 | Nord: A Functional Typology of Translations 13

2.1.1 | Introduction: Towards Functionalism 13

2.1.2 | Translation Type and Communicative Function 14

2.1.3 | Translation Problems 16

2.2 | Chesterman's Translation Norms and Strategies 19

2.3 | Conclusion 20

Chapter Three
Medical Texts for Young Patients

3.1 | Introduction: A Very Short History 21

3.2 | The Problem of Terminology 22

3.3 | Translating Medical Terminology 23

3.4 | Medical Texts for Patients 24

3.5 | Writing Texts for Teens 25

3.6 | Conclusion 27

Chapter Four
Marfan Syndrome

4.1 | Marfan Syndrome 28

4.2 | Marfan in the Netherlands 31

4.3 | Marfan in the United States of America 32

4.4 | Teens with Marfan 34

4.5 | Conclusion 35

Chapter Five
Translation Analysis

5.1 | Introduction 36

5.2 | Target Text Analaysis 36

5.3 | Source Text Analaysis 37

5.4 | Translation Problems in *Teens with Marfan* 39

5.4.1 | Pragmatic Translation Problems 39

5.4.2 | Intercultural Translation Problems 39

5.4.3 | Interlingual Translation Problems 40

5.4.4 | Text-specific Translation Problems 40

5.5 | Conclusion 40

Chapter Six

Annotated Translation of *Marfan for Teens*

6.1 | Introductions

6.1.1 | Parent's Introduction 41

6.1.2 | Teens' Introduction 43

6.2 | Chapter 2: What Is Marfan Syndrome?

6.2.1 | Main Text 45

6.2.2 | Teen Perspective 46

6.2.3 | Marfacts 46

6.2.4 | Helpful Hints 46

6.3 | Chapter 3: How Is Marfan Syndrome Diagnosed?

6.3.1 | Main Text 48

6.3.2 | Marfacts 49

6.4 | Chapter 4: How Is Marfan Syndrome Treated?

6.4.1 | Main Text 50

6.4.2 | Teen Perspective 51

6.4.3 | Marfacts 51

6.4.4 | Helpful Hints 52

6.4.5 | Good Advice 52

6.4.6 | Text Without Header 53

6.5 | Chapter 5: Living With Marfan Syndrome

6.5.1 | Main Text 54

6.5.2 | Teen Perspective 55

6.5.3 | Helpful Hints 58

6.5.4 | Good Advice 58

6.6 | Chapter 6: Preparing for Your Future

6.6.1 | Main Text 59

6.6.2 | Teen Perspective 60

6.6.3 | Marfacts 61

6.6.4 | Helpful Hints 61

6.6.5 | Good Advice 61

6.7 | Resources 62

6.8 | Glossary 63

6.9 | Bibliography 63

6.10 | Illustrations 63

List of Works Cited 64

Appendix 1
Translation Notes 69

Appendix 2
Examples of Original Source Text 81

[Chapter One]

Introduction

§ 1.1 | Marfan Syndrome: A Guide for Teens

This thesis is based on an actual translation assignment that was commissioned in 2007 by Stichting Hoofd, Hart en Vaten (Foundation for Head, Heart and Blood Vessels), my employer at that time. They represent the interests of seven Dutch patient associations, among which the Contactgroep Marfan Nederland (CMN). The CMN intend to assist people with Marfan syndrome by increasing awareness about Marfan syndrome among medical specialists, scientists and the general public.[1] In order to make use of knowledge and experience of other Marfan organisations around the world, the CMN are a member of the International Federation of Marfan Syndrome Organizations (IFMSO), whose purposes include to '[s]hare current, accurate information about the Marfan syndrome worldwide and facilitate international communication among medical professionals and the general public'.[2] The largest Marfan organisation in this international network is the National Marfan Foundation (NMF) from the United States of America. The CMN asked me to translate patient information from the NMF website into Dutch, as well as *Marfan Syndrome: A Guide for Teens*, a small booklet (45 pages) for teens who have Marfan syndrome that gives them support and advise. More information on the CMN and the NMF will be included in chapter four of this thesis. A representative selection of the booklet will be included in Appendix two. Although eventually, I did not translate the booklet, I did become interested in medical translation, especially in translating medical texts for patients. In 2008, I wrote a short academic paper on this subject, which partly serves as a starting point for this thesis.

The NMF issued *Marfan Syndrome: A Guide for Teens* in 2006. In a special insert for parents, the NMF sum up their intentions: 'Teens with Marfan syndrome have special need to become adults able to manage their medical care. We hope this booklet will guide teens as they move from care directed by their parents to care directed by themselves. We hope teens will find comfort in knowing they are not alone and will find inspiration from those who have shared their stories with us'.[3] Rather than being just a reference work or a manual, this booklet is meant to coach, to comfort and to connect to teens with Marfan and their parents.

The booklet contains various elements. Beside the main text, there are short quotations and remarks throughout the booklet that are labelled 'Marfacts' (hard facts about Marfan, such

[1] Contactgroep Marfan Nederland. "De Contactgroep Marfan Nederland," 2010. *Marfansyndroom*. Web. 15 Jan. 2011.
[2] International Federation of Marfan Syndrome Organizations. "IFMSO Mission," 2005. *Marfanworld*. Web. 25 May 2011.
[3] National Marfan Foundation. Marfan Syndrome: A Guide for Teens (New York: NMF, 2006) insert for parents.

as the 1 out of 2 chance to inherit Marfan from your parents), 'Teen Perspective' (quotes from other teens expressing the way they deal mentally with their disorder), 'Helpful Hints' (pedagogical remarks in disguise - "do take your medication!"), or 'Good Advice' (more pedagogical remarks in another disguise). The text is illuminated with large monochrome photographs on every page, mostly depicting other teens with Marfan syndrome, but also parents, doctors and details of typical Marfan-related physical features. These are more than just decorations, as they will also provide readers with recognition and maybe even lower the threshold to medical treatment.

The main text contains information and advice about the nature, diagnosis and treatment of Marfan, ways to live with the disorder and how to prepare for a relatively healthy and satisfying future, as well as a call to participate in the Marfan community by joining NMF events. It concludes with a glossary of medical terminology and a list of resources for further reading.

§ 1.2 | **Research Question**

The purpose of this thesis is to analyse which translation problems occur when translating *Marfan Syndrome: A Guide for Teens* for the Dutch patient union Contactgroep Marfan Nederland, to investigate possible solutions and to propose the best solutions to those translation problems.

§ 1.3 | **Method**

As mentioned before, *Marfan Syndrome: A Guide for Teens* is meant to have an impact on teens with Marfan syndrome, rather than being a mere reference work or a manual. As this property makes up a vital aspect of the text, it is evident that the translator should take into account how the original text (the Source Text or ST) functions in the United States and how its translation (the Target Text or TT) should function in the Netherlands, and to what extent those functions should be similar. Is the TT primarily supposed to inform the Dutch audience about American Marfan resources, or should it, like the ST, actually influence the emotions and the behaviour of its readers? And to what extent should the TT really be identical to the ST when it comes to the approach towards Marfan syndrome, the approach towards the reader and even the actual subject matter of the text? These questions make clear that the nature of the TT is closely related to extratextual factors, such as the Target Culture (TC) and the person who or institution that decides what the nature of the TT is to be. On the other hand, it is intuitive that the TT cannot deviate from the ST without constraint and still be considered a faithful translation. Indeed, the translator should always exercise loyalty towards the ST, as well as towards the commissioner of the translation assignment.

One strand in the field of translation studies that takes both textual and extratextual factors into account is functionalism. In his introduction to translation studies, Mason remarks that functional approaches 'broadly represent a view which refuses to divorce the act of translating from its context, insisting upon the the real-world situational factors which are prime determinants of meaning and interpretation of meaning'.[4] Mason specifically mentions Christiane Nord, a functionalist translation scholar who bases her ideas upon the notion of text functions, a concept that stems from communication theory. According to Nord, the essence of a translation is defined by the way it will function in its target culture, and the way it will affect its target audience. In addition to that, she considers loyalty an indispensible part of the translation process. Since the function of *Marfan Syndrome: A Guide for Teens* is inextricably linked to its contents, Nord's model is indeed suitable for providing a theoretical framework for its translation.

Whereas the communicative functions of a text and the loyalty principle make up the rationale of Nord's view, she does not leave it at that. Nord embeds her ideas in a rather detailed model of the translation process itself, which does not only serve to include all possible functions in the translation procedure, but which should also make it more efficient and less prone to errors than 'the "normal" [translation] procedure',[5] by which she means 'to transfer the text … if possible even word by word in a kind of draft translation, and then try and polish it stylistically'.[6] Nord alternatively suggests a profound analysis of the communicative situation of both the TT and the ST, a comparison of both outcomes, an inventory of the translation problems that arise, and a decision on the best way to deal with those translation problems.[7]

Although Nord's plea for including communicative functions in the translation process is quite valuable to the translation of *Marfan Syndrome: A Guide for Teens*, her model eventually leaves the solution of specific translation problems largely to the translator's intuition.[8] This is somewhat contradictory to her emphasis on loyalty. After all, a loyal translator should be able to justify his translation choices in a consistent manner. Andrew Chesterman suggests a classification of translation strategies that can be very useful to deal with translation problems consistently. Chesterman's classification consists of four translation norms which a translation must meet. He subsequently provides 30 translation strategies that should help a translator to conform to those norms. Specific translation problems can be solved by the application of (a combination of) grammatical, semantic and pragmatic strategies. Chesterman's intricate linguistic scheme is an attempt to 'structure

[4] Ian Mason. "Communicative/ functional approaches." Routledge Encyclopedia of Translation Studies. 1st ed. 2001: 29.
[5] Christiane Nord. "A Functional Typology of Translation, " Text Typology and Translation. (1997): 62.
[6] Nord, Typology 62.
[7] Nord Typology 58.
[8] Nord Typology 63.

various proposals made by other scholars, [such as Vinay and Darbelnet (1958), Nida (1964), and Leuven-Zwart (1989/1990)], into an overall framework'.[9] Particularly Nida is notable in this list, because of his controversial but groundbreaking plea for dynamic equivalence ('the relationship between receptor and message should be substantially the same as that which existed between the original receptors and the message').[10]

Although functionalism and linguistics are quite useful to the translation of *Marfan Syndrome: A Guide for Teens*, these schools of translation studies have received criticism from other translation scholars. One example is the way in which functionalism separates the message of a text from its form (i.e. the actual words and sentences). Nord's focus on function as the real message of the text, albeit combined with a reference to loyalty, is allegedly idealistic, semi-religious and non-scientific. In the eyes of critics, the 'message' is an elusive concept that cannot be defined according to objectively measurable standards. Apart from that, the functionalist emphasis on the target audience as part of the translation process could make the translator susceptible to questionable influences, like Nida was willing to go to great lengths to convert the readers of his Bible translation to Christianity. Edwin Gentzler summarises those objections by stating that 'the existing "sciences" of translation and functionalist training programs are still largely based upon concepts rooted in religion ... and, most recently, economic forces. The deep-structure/surface-structure approach seems always to posit some sort of hypothetical invariant, be it the syntax, semantics, or function, which is consistent and unified, and to which competent translators and astute critics are seen as having access ... As Nida has missionary motives behind his dynamic equivalence and his "science" of translation, so too does the functionalist approach seem to have a sales mission behind its functional equivalence'.[11]

Gentzler may be rightly critical about the risks and philosophical deficits of functionalism and linguistics, but his downright scepticism towards these views does not fully do justice to their explicit benefits. His first objection concerns the mystical nature of the notion of function, syntax or semantics. However, both Nord and Chesterman actually offer intuitive and elegant methods to describe this 'invariant', which are even solidly embedded in communication theory and linguistics. Gentzler's second objection to functionalism and linguistics has to do with the motives behind translation choices. This is indeed a valid argument that could help prevent racism, sexism and cultural annexation, especially in sensitive texts such as religious, literary or political documents. It applies less to other text types, as Gentzler also concedes: 'it lends itself particularly well to translating ... advertisements, brochures, product descriptions, and marketing items'.[12] The translation models of Nord and Chesterman offer an applicable and coherent system for the translation

[9] Andrew Chesterman, Memes of Translation (Amsterdam / Philadelphia: John Benjamins, 1997) 92-93.
[10] Eugene Nida. "Toward a science of translating," Introducing Translation Studies. (2001): 42.
[11] Edwin Gentzler, Contemporary Translation Studies (New York: Multilingual Matters Ltd., 2001) 74-75.
[12] Gentzler 73.

of *Marfan Syndrome: A Guide for Teens*. Similar to commercial writing, this text may have the purpose to convince people, but ethically it has fully justifiable objectives.

The next chapter of this thesis will be devoted to a more detailed exposition of Nord's and Chestermans theories. Nord's theory will mainly serve to identify translation problems in *Marfan* Syndrome, whereas Chesterman's theory will rather offer suitable solutions to those problems. Chapter three and four will subsequently go into medical writing and Marfan syndrome, in order to contrast the TT and ST in more detail. Chapter five will be a translation analysis, based on the preceding chapters. Chapter six contains the source text and target text of this translation assignment, including an appendix with footnotes that describe what translation solution was made, and why. The second appendix contains a representative selection of the Source Text.

[Chapter Two]

Theoretical Framework

§ 2.1 | Nord: A Functional Typology of Translations

§ 2.1.1 | Introduction: Towards Functionalism

The purpose of this thesis is to define the translation problems in *Marfan Syndrome: A Guide for Teens* and the solutions to those problems. Translation problems may occur because languages have a different grammar, because concepts from the source text are unknown or have a different meaning in the target culture, because jokes can hardly be translated, and for several other reasons.

It has been clear from very early on in translation history that the translation of a text involves more than simply replacing a word in the source language with its counterpart in the target language. As early as in the first century BC, Cicero commented on his own translation of the Attic orators, stating that he 'did not translate them as an interpreter, but as an orator ... I did not hold it necessary to render word for word, but I preserved the general style and force of the language'.[13] If Cicero had restricted himself to a 'literal' translation, the persuasiveness of the orations would at least have been diminished. Various schools of translation studies have since then suggested methods and ideas to refine this broad distinction. In the late 1940s, Eugene Nida introduced the concept of dynamic equivalence,[14] to state that words from the source text and the target text of a translation should have 'the same effect on their respective readers'.[15] Although the notion of equivalence is still 'a central concept in translation theory ... it is also a controversial one.'[16] After all, a translation is always a representative of the source text in a different language. Therefore, loyalty to the source text is essential for a good translation. Despite the controversy, Nida did make clear that the intended reader cannot be ignored altogether in the translation process.

In 1978, Hans J. Vermeer took up this notion as he proposed the so called skopos theory. The term has been derived from the Greek word σκοπός (skopós), meaning scope or purpose. The idea is that 'the intended purpose of the target text ... determines translation methods and strategies'.[17] Note that the target text takes a central position in this theory, thus relating to Nida's argument for the target reader. However, skopos goes beyond equivalence. 'In this functional view of translation, any notion of equivalence between a

[13] Marcus Tullius Cicero. "De optimo genere oratorum," Introducing Translation Studies. (2001): 19.
[14] Nord, Typology 43.
[15] Dorothy Kenny. "Equivalence." Routledge Encyclopedia of Translation Studies. 1st ed. 2001: 77.
[16] Kenny 77.
[17] Christina Schäffner. "*Skopos* Theory." Routledge Encyclopedia of Translation Studies. 1st ed. 2001: 235.

source text and a target text is subordinate to the *skopos*, or purpose which the text is intended to fulfil. Adequacy with regard to *skopos* then replaces equivalence as the standard for judging translations.'[18] While Nida still takes the effect of the ST on its readers as a starting point, the skopos theory is centered around the purpose of the TT. This is a further emancipation of the target reader, but its weakness is still its loyalty towards the ST.

Christiane Nord suggests a functional translation theory which, like skopos theory, starts out from the way a TT will function in its context. However, in order to prevent excessive independence from the ST, she suggest the 'loyalty principle'.[19] A competent translator should always be loyal to the author of the ST, as well as to the commissioner of the translation. The expectations of the commissioner are to be specified and agreed upon by the translator in a so called translation brief, at the beginning of the translation process.

§ 2.1.2 | Translation Type and Communicative Function

Nord approaches a text as a 'communicative occurrence', that is set in a 'communicative situation'. A text is a message that is transferred from a sender to a receiver, through a suitable medium and with the function 'of fulfilling the communicative purpose intended by the sender'. However, 'as we all know, the best of intentions does not guarantee a perfect result' and therefore the receiver 'completes the communicative action by deciding to receive the text in a particular function'. This receiver's decision may well differ from the intention of the sender. Nord concludes that 'the function of the source text is specific to the original situation', while the 'function of the target text ... is specific to the target situation'. In other words, 'it is an illusion that a target text should have *automatically* the "same" function as the original.' [20]

Nord suggests to use the four basic textual functions from Bühler and Jacobson as 'a frame of reference for functional analysis'. Those functions include the referential, the expressive, the appellative, and the phatic function of a text. All of those functions occur in the following fragment from *Marfan Syndrome: A Guide for Teens.*

> Dear Parents,
>
> The National Marfan Foundation is pleased to provide this booklet written for teens affected with Marfan syndrome. Although the booklet is written for teens, we encourage you to read it also. Perhaps it will serve as a starting point for talking with your teen about what it means to have Marfan syndrome.[21]

[18] Mason 32.
[19] Nord, Typology 48.
[20] Nord, Typology 49.
[21] National Marfan Foundation, insert for parents.

- The *referential function* of this text is the way in which it refers to 'objects and phenomena around the world', such as the booklet itself, the NMF, Marfan syndrome, and the relationship between parents and teens.

- The *expressive function* of this text is the way in which it expresses 'the sender's attitude or feelings towards the objects and phenomena dealt with in the text'. The sender of the fragment above expresses how they care about the relationship between teens with Marfan syndrome and their parents.

- The *appellative function* of the text is the way in which it appeals 'to the receiver's experience, feelings, knowledge, sensibility, etc. in order to induce him/her to react in an specific way.' In the fragment, parents are encouraged to read the booklet that has been written primarily for their children, by stating that it can lead to an open conversation with their teen about Marfan syndrome.

- The *phatic function* of the text refers to the way in which it can 'establish, maintain or finish contact'. In the text above, the salutation 'Dear parents' indicates the phatic function of the fragment. [22]

Beside the text function, the *type of translation* should also be taken into account by translators. Nord distinguishes two translation types: the translation can be (1) a *document* ('a kind of metatext marked as a translation') [23] or (2) an *instrument* (a text 'which can serve any function a non-translated text can achieve').[24] An example of a document is a literary translation, including translator's notes, that clearly expresses how it is a foreign text and how its foreign aspects are actually an indispensable property of the translation. Instruments are translations of an ST that do not need to remain visible themselves, such as text books, newspaper articles and instruction leaflets. The TT of *Marfan Syndrome: A Guide for Teens* can typically be described as an instrument, since it is meant to provide help for patients in the exact same way as any other medical text for patients in Dutch.

The type of translation has a causal relationship with the function of the target text and the source text. Nord gives some examples of subsets of instrumental translations: 'if the function of the target text is the same as that of the original, we can speak of an "equifunctional translation"', whereas 'if the function or functions cannot be reproduced as a whole or in the same hierarchy of functions, we could speak of a "heterofunctional" translation'[25]. If it turned out from the translation brief of *Marfan Syndrome: A Guide for*

[22] Nord, Typology 50-51.
[23] Nord, Typology 51.
[24] Nord, Typology 52.
[25] Nord, Typology 53.

Teens that the CMN would like the translation to be more distant and formal than the original text, the translation would be heterofunctional. Yet, even if the translation is equifunctional, an analysis of the TT and ST´s communicative functions is quite valuable, because a translator can only render identical functions if he is aware of those functions, and even identical functions may cause translation problems - the preservation of the referential function of *Marfan Syndrome: A Guide for Teens* actually requires an adaptation of several realia (culture specific items), to give just one example.

§ 2.1.3 | Translation Problems

In order to systematically identify possible translation problems, Nord suggest a comparison of the source text and the target text. Because, according to Nord's model, the communicative functions of a translation are closely related to the target situation, 'the process of producing a "functional" target text has to start ... from an analysis of the target situation'.[26] Of course, there is no translation yet at this stage of the translation process. However, various aspects of the target text are known already from the result of the translation brief. Based upon this translation brief, a translator should ask the following question to determine the skopos of the target text:

> 'Who writes with what purpose to whom over which medium where and when and why a text with which function? What does he say (and not say) in what order, using which non-verbal elements, with which words, in which sentences, at which tone, with which effect?'[27]

After analysing the target text, the translator should analyse the source text likewise. As a translator compares the skopos with the result of the source text analysis, 'the translator will find out (a) whether the assignment can be fulfilled without violating the loyalty principle and (b) which translation problems will arise in the process and what kind of transfer procedures will have to be used in order to solve them'. [28] If a translator would conclude from the translation brief that he is not competent enough to produce a translation according to the expectations of the commissioner, or if he would conclude that the expectations of the commissioner are unrealistic, he would violate the loyalty principle by ignoring those considerations.

Nord identifies four categories of possible translation problems: they can be pragmatic, intercultural, interlingual or text-specific.

---

[26] Nord, Typology 55.
[27] Christiane Nord. "Tekstanalyse en de moeilijkheidsgraad van een vertaling." Denken over Vertalen. 1st ed. (2004): 235.
[28] Nord, Typology 58.

- *Pragmatic translation problems* (PTP) are the result of the contrast between the ST situation and the TT situation, such as culture-bound terms that presuppose knowledge of the source culture.[29] An example of this in *Marfan Syndrome: A Guide for Teens* is the very name of the patient organisation: Dutch readers cannot be referred to the American NMF for answers to their questions.

- *Intercultural translation problems* (CTP) 'arise from the differences between the two cultures involved, such as measuring conventions, formal conventions ... conventional forms of address and salutation formulae'.[30] An example would be the conversion of miles into kilometres, or the Dutch convention for writing telephone numbers.

- *Interlingual translation problems* (LTP) are caused by '[t]he structural differences in vocabulary, syntax and suprasegmental features of the two languages'.[31] *Marfan Syndrome: A Guide for Teens* contains several lists, and an LTP would arise if Dutch grammar would not allow an identical construction, such as 'The need for aortic surgery is determined by: - whether or not the aortic valve is leaking'. A Dutch rendition of this sentence would require a different word order, such as 'Of aortachirurgie nodig is, hangt af van: - het wel of niet lekken van de hartklep'.

- *Text-specific translation problems* (TTP) 'are those problems which arise in the translation of one specific text and whose solution cannot be generalized, although it is also based on functional criteria'[32], such as 'metaphors, similes, puns, rhetorical figures'.[33] *Marfan Syndrome: A Guide for Teens* regularly makes puns based on the word Marfan, such as Marfantastic or Marfacts. Those puns are specific to publications from the NMF, and perhaps even specific to this text.

Nord concludes her model by recommending a functional hierarchy of translation problems. After a translator has assessed the translation assignment, he should:

1. decide whether the translation should be documentary, or rather instrumental
2. decide 'which functional elements of the ST will have to be reproduced "as such" and which should be adapted to the adressee's background knowledge, expectations, communicative needs, to medium-restrictions, deixis-requirements, etc.
3. decide whether to reproduce the source-language norms, or rather to adapt to the target-language norms
4. decide which context-bound factors are relevant
5. only after that should translators rely on their own intuition.[34]

[29] Nord, Typology 59.
[30] Nord, Typology 59.
[31] Nord, Typology 60.
[32] Nord, Typology 61.
[33] Nord, Typology 61.
[34] Nord, Typology 63-64.

A clear advantage of Nord's theory is that a translator is motivated to approach a translation strategically, which allows him to use solutions to translation problems consistently. Another asset of her view is that her analysis makes the translator aware of the nature of the translation assignment and gives him instruments to deal consciously with its characteristics. More importantly, her functional approach advocates the interests of the target reader, which allows for a tailor made final product. Especially for the translation of medical texts for patients, such as *Marfan Syndrome: A Guide for Teens,* that is crucial to their effectiveness. Her loyalty principle secures the necessary coherence with the ST to some extent. Based on the intended communicative functions of a translation and a thorough analysis of the TT and ST, Nord offers a systematic way to identify a set of complementary translation problems. Chapter five of this thesis is a detailed analysis of *Marfan Syndrome: A Guide for Teens*, based on this model.

Although Nord's model does offer a suitable way to map the translation problems in *Marfan Syndrome: A Guide for Teens*, it does not suffice to answer the entire research question of this thesis. The solution to translation problems that Nord provides predominantly concerns the overall level of the translation. It is true that in her analysis, she mentions the word-level of the text, but eventually, she leaves detailed translation choices to the translator's preference. Another downside of Nord's view is her relatively general definition of the loyalty principle. Andrew Chesterman has proposed a translation theory that overcomes both of these shortcomings.

§ 2.2| **Chesterman's Translation Norms and Strategies**

Andrew Chesterman agrees with Nord's emphasis on loyalty. He defines translation norms, which are the foundation of his theory, as ideas about translation 'which are accepted ... by a community as being conducive to behaviour perceived as useful'.[35] Chesterman's norms include (a) the *accountability* norm (a translator should always be loyal to all parties concerned), (b) the *communication* norm (a translator should optimise communication, in its widest sense) and (c) the *relation* norm (a translator should maintain an appropriate relation between source and target texts).[36] According to Chesterman, translators can conform to translation norms by using specific translation strategies. Like Nord's theory, Chesterman's strategies explicitly apply to the target text. Strategies should be applied 'if [a translator is] not satisfied with the target version [of the target text] that comes immediately to mind - because it seems ungrammatical, or semantically odd, or pragmatically weak, or whatever.'[37]

Chesterman's initial suggestion to cope with translation problems seems fairly simple: if a translator faces a problem in the target text, he should 'change something in it'.[38] However, he offers 3 groups of 10 translation strategies to allow for coherent and systematic changes throughout the TT. This is exactly how Chesterman's theory begins where Nord's theory ends (and vice versa): whereas Nord provides a systematic way to define the translator's dissatisfaction, Chesterman's translation norms and strategies offer a systematic method to solve these translation problems.

Translation strategies can be either syntactic, semantic, or pragmatic. Whereas 'syntactic strategies manipulate form ... semantic strategies manipulate meaning [and] pragmatic strategies ... manipulate the message itself'.[39]

Syntactic / grammatical strategies include literal translation, loan / calque, transposition, unit shift, phrase structure change, clause structure change, sentence structure change, cohesion change, level shift, and scheme change.

Semantic strategies include synonomy, antonomy, hyponomy, converses, abstraction change, distribution change, emphasis change, paraphrase, trope change, and other semantic changes.

Pragmatic strategies include cultural filtering, explicitness change, information change, interpersonal change, illocutionary change, coherence change, partial translation, visibility change, transediting, and other pragmatic changes.[40]

[35] Chesterman 88.
[36] Chesterman 88.
[37] Chesterman 88.
[38] Chesterman 88.
[39] Chesterman 107.
[40] Chesterman 107.

Examples of the various strategies will be part of the translation analysis in chapter five of this thesis, and they can be found throughout the translation notes in appendix one.

Chesterman's translation strategies concern all possible levels of a translation: its grammar, its meaning and its structure. Since these aspects are complementary, strategies from different groups will often occur in the same text fragment simultaneously. While Nord's theory makes the translator aware of translation problems, Chesterman's theory gives the translator an instrument to consider a suitable combination of solutions. At first, it may cost the translator some time to realize the full potential of Chesterman's system, but to an experienced translator the categories will serve as an intuitive tool for delivering consistent solutions to similar problems.

§ 2.3 | **Conclusion**

Whereas Nord's theory includes a very specific and well-defined view on translation problems, Chesterman's definition is quite simple: 'change something'. However, these approaches to translation problems can be complementary, since Nord mainly intends to generalise, while Chesterman also focuses on specific translation problems 'on the fly' during the translation process. Nord's question covers the entire area from full text to single word, but her hierarchy ultimately leaves decisions up to the translator's intuition. In the context of Nord's theory, Chesterman's translation strategies come in at the moment where Nord leaves the decision to the translator's preference. When an analysis according to Nord leads to translation problems, Chesterman's strategies are the solutions. The translation norms justify / predict the selected strategy, which solves a perceived translation problem, both on the general level and the incidental level of the translation process.

[Chapter Three]

Medical Texts for Young Patients

§ 3.1 | Introduction: A Very Short History

Medical translation is as old as medical writing. McMorrow concludes that medical texts in all major Western languages can be reduced to written texts in Greek civilizations (500 – 30 BC). He expounds the development of medical writing as follows. Of all sciences, medical science has one of the longest written traditions. Medical knowledge was cherished and carefully passed on to posterity. This holds true for all great civilizations (India, China, the Middle East and Europe), but as stated previously, the scientific method that is used nowadays in Europe and the United States of America dates back to ancient Greece. This Greek knowledge was adopted by the Roman Empire (100 BC – 400 AD). With medical knowledge, medical language was preserved as well. McMorrow explains this by push and pull factors. When a culture develops knowledge, it coins accompanying terminology in its own language. These terms are pushed into the language of an 'inferior' culture (push factor). An inferior culture in this context means a culture that does not yet have certain knowledge in their own language. For example, Italian language plays an important role in Western musical terminology, since 'many of the most important early composers in the renaissance period were Italian, and that period is when numerous musical indications were used extensively for the first time'.[41] On the other hand, it is easier for a receiving culture to adopt new knowledge including terminology (pull factor).

However, Greek medical terminology did not survive in Europe directly. Whereas Europe gradually lost interest in its classic heritage, Greek medicine was still admired in the Byzantine Empire. Therefore, Greek manuscripts were studied throughout Southern Europe and Northern Africa during the Middle Ages. By the time of the Renaissance, a renewed interest in these original manuscripts arose in Europe. Greek affixes were smoothly applied onto Latin, which was the official academic language until ca. 1800. Medical science was from then on expressed in this mixture of Greek and Latin and that still holds true for all medical texts in Western Europe.

In this period, medical texts were often translated for a lay audience, among others because many doctors had not been trained at academic level. From the late Middle Ages, lay people also had the knowledge and means to write down their own medical awareness. This means that medical writers and translators could choose words from scientific Latin or from the vernacular language. Besides, the influence of research in adjacent fields of science

[41] Wikipedia. "Italian musical terms used in English," 10 May 2011. *Wikipedia*. Web. 24 May 2011.

increased, and it still does. As a result, in the 21st century there is often 'quasi-uniformity' among medical terms in different Western European languages.[42]

In the past, medical translation may have been relatively easy 'because progress in the medical sciences was comparatively slow and the translator's task was simplified by the fact that the basic anatomical and physiological elements of medical communication were largely the same all over the world'. Pilegaard (in Trosborg 1997, p.161) states that nowadays, medical translation has actually become quite difficult 'with the current pace and proliferation of medical research … [N]ew names are being constructed daily by researchers, with little coordination'.[43] From a recent corpus research project it turned out that the English language in general produces around 8,500 new words every year and that the total number of English words has increased from ca. 600,000 in 1950 to over one million in 2000.[44] Apart from neologisms, Pilegaard also discerns complicating factors such as medical homonymy, the use of professional jargon, and the poor writing skills of medical specialists.

§ 3.2 | The Problem of Terminology

Like almost any text, medical texts partly consist of everyday terms and concepts, especially when they have been written for patients. Sauer describes this general use of language as 'Language for General Purposes' (LGP).[45] However, it is typical for medical texts that they also contain specific terminology that is used exclusively in a medical context. Picht and Draskau define terminology that is almost exclusively used in one or in a few fields or academic disciplines as 'Language for Special Purposes'(LSP)[46]. The most striking property of the medical variant of LSP is the great number of Greek and Latin stems, prefixes and suffixes. In general, patients are not familiar with this terminology.

In a study concerning the explanation of medical terminology by doctors to patients, Teunissen and Jacobs state that in the Netherlands, it is a legal obligation that patients be fully informed about their health and the suggested treatment before further research and treatment is allowed. The patient must have understood this information.[47] The use and explanation of medical terms can influence the relationship between a doctor and a patient. Professional jargon seems pre-eminently reserved for the doctor, who is apparently in

[42] Leon McMorrow. "Breaking the Greco-Roman Mould in Medical Writing: The Many Languages of 20th century medicine," Translation and Medicine. (1998): 13.
[43] Morten Pilegaard. "Translation of Medical Research Articles," Text Typology and Translation. (1997): 162.
[44] Lucas Brouwers. "Digitaal Doorvlooien." NRC Handelsblad. 15 Jan. 2011, Wetenschap: 10.
[45] Christoph Sauer. "Vaktaalkennis," Metaphors in Modern Medicine. (1994): 5.
[46] Heribert Picht and Jennifer Draskau. "Terminology: An Introduction," A non-specialist approach to defining medical language. (1988): 4.
[47] Mariëtte Teunissen and Geert Jacobs. "Oh, u bedoelt dat ik een hoge bloeddruk heb? Over het uitleggen van medische vaktermen in arts-patiëntgesprekken," Over de grenzen van de taalbeheersing. (2000): 427.

charge of the conversation.[48] However, using medical terminology actually empowers the patient, so the use of medical terms (with or without explanation) is very important for the success of information transfer from doctor to patient. According to Teunissen and Jacobs, it is better to explain a term before actually mentioning it. Through the use of this order, it is easier for the patient to remember the term and its meaning.[49]

Explanation of medical terms can be 'exposed' or 'implicit'. This has an influence on the balance of power between patient and doctor. If the explanation is more exposed, the doctor is more powerful. On the other hand, more explicit explanation makes it clearer that the meaning of a term indeed comes across to the patient.[50] Patients do not tend to ask for explanation. Therefore it is important to explain terminology pro-actively. Yet, it is not always necessary to explain terminology: patients begin to use these terms as well after a while, which makes communication more equal / symmetrical and less ambiguous.[51]

Doctors should be trained to realise that the use of terminology has influence on patient information and they must be aware that the way they use medical terminology affects their relationship with patients. [52] Obviously, the same is true for authors of medical texts.

§ 3.3 | **Translating Medical Terminology**

The translation of medical terminology from English to Dutch poses its very own challenges. As stated earlier, medical texts contain terminology from Greek and Latin. This is true for both Dutch and English, and several other Western languages, as a result of their shared history. Hence, the relationship between medical terminology in English and Dutch can clearly be recognised.

Unfortunately, related words in both languages are not identical. Robert Lankamp clarifies this by comparing *vena cava inferior (Dutch)* to *inferior vena cava* (English). He divides the differences between Dutch and English medical terminology into conjugational contrasts and lexical contrasts. His example of a conjugational contrast is the English word 'tubular' versus the Dutch word 'tubulair'. Lexical contrasts can be subdivided into formal contrast, seeming relationship and register error. There is formal contrast when the Dutch word for a specific concept is clearly not related to the English word for the same concept (English 'vasculature' versus Dutch 'vaatsysteem'). When a term in one language is similar to a word in another language and yet it refers to a different concept, that is called seeming relationship (English 'German measles' versus Dutch 'mazelen'). According to Lankamp, seeming relationship hardly occurs in medical terminology, perhaps because of the confusion it causes. A register

[48] Teunissen and Jacobs 427.
[49] Teunissen and Jacobs 430.
[50] Teunissen and Jacobs 431.
[51] Teunissen and Jacobs 433.
[52] Teunissen and Jacobs 437.

error is a word that is used only by specialists in one language, whereas it is part of everyday speech in the other language. For this, Lankamp gives the example of 'appendicitis' (English) versus 'appendicitis / blindedarmontsteking' (Dutch).[53]

§ 3.4 | **Medical Texts for Patients**

Medical texts are of course not a monolithic text type. Montalt Resurrecció and Gonzalez Davies mention four categories of medical writing: *research genres* (including texts like research papers, clinical trial protocols and docotoral theses), *professional genres* (such as informed consents, medical questionnaires and medical histories), *educational genres* (among others including patient information leaflets, popularising articles, and fact sheets for patients), and *commercial genres* (examples of these are contracts, product information leaflets, and packaging inserts). In this classification, a text like *Marfan Syndrome: A Guide for Teens* would be considered a fact sheet for patients, and as such an educational text type, typically written with the purpose of providing patients with basic and practical information about their condition and normally issued by a health organisation.[54]

Verónica Albin states that LSP and LGP are most strongly confronted with each other in medical texts that are targeted at a broad audience. Patient information is meant for such a broad audience: diseases occur among all layers of the population, including people with poor language skills. Therefore it is important that medical information be formulated in a plain and comprehensible way, without compromising precision of meaning. Albin rejects to just leave out medical terminology. She gives three reasons for that: terminology is unambiguous; terminology is standardized; and terminology eases communication between patient and medical professional during treatment.[55]

[53] Robert Lankamp, A non-specialist approach to defining medical language (Leiden: Rijksuniversiteit te Leiden, 1998) 15.
[54] Vicent Montalt Resurrecció and María Gonzalez Davies, Medical Translation Step by Step: Learning by Drafting (Manchester, UK and Kinderhook, USA, 2007): 62.
[55] Verónica Albin. "Translating and Formatting Medical Texts for Patients with Low Literacy Skills." Translation and Medicine. (1998): 117.

In order to simplify medical texts nonetheless, Albin suggest the following criteria for writing plain medical texts:

Text that is easy to read and understand has:	A poorly legible / readable text contains certain items and characteristics, including the following:
Short, simple words	Long, complex words
Short sentences	Long sentences
Parallelism	Lack of parallelism
Concrete language	Abstract language
Text markers (such as transitional phrases), which permit the reader to anticipate what is to come	Referenced material (such as endnotes, footnotes, superscripts, captions, etc.)
Repetitions as reinforcement	No reinforcement
Vertical lists; numbered when sequence is important, bulleted, or otherwise	Horizontal lists
Alphabetical lists (when appropriate)	Non-alphabetical lists
Logical placement of the verb	Complicated syntax
Simple verb tenses (imperative mood, past, present and simple future)	Complicated verb tenses (subjunctive, compound tenses)
Active voice	Passive voice[56]

Albin's suggestions are definitely useful, logical and they fit well with the conclusions of Teunissen and Jacobs: it is better to mention terminology and to include an explanation than to leave it out altogether. When Albin's view is consistently applied to the translation of *Marfan Syndrome: A Guide for Teens*, that may even result in an adaptation of the text, if the ST does not comply with Albin's conditions. From a functionalist point of view, that actually is exactly what a translator should do, as his intention is to achieve the purpose of the TT in the best possible way. In order to prevent violation of the loyalty principle, he should discuss this with the commissioner of the translation. A pragmatic translation strategy, such as information change or change of explicitness, could be a suitable solution to this type of translation problems.

[56] Albin 123.

§ 3.5 | **Writing Texts for Teens**

According to the CMN, who commissioned the translation of *Marfan Syndrome: A Guide for Teens,* the ST has been written for people from 13 - 19 years old. In the Netherlands, people from this age group generally tend to use a different register than the style that is normally used by adults. This specific register is denoted as youth language. Youth language is a relatively new phenomenon in the Netherlands. It came up with the civilisation process in the 18th century. Before 1864, only 4% of all children of twelve and above went to school – the others mixed with adult society. This percentage rose to 12% in 1930, 33% in 1950 and has been nearly 100% since the early seventies, when the obligatory nature of education was extended. Hence, youth in the Netherlands has more and more become a separate social group with its own identity, and a shared youth language binds them together.[57]

In that sense, youth language is comparable to other subgroup languages, such as soldier language and student language. Youth language is the contemporary version of a regional dialect. As with dialects, student language and soldier language, the peer group plays an important role in creating youth language. That mostly concerns terminology about topics such as haircut and clothing, music and the way in which leisure time is spent, as well as opinions on behaviour and appearance. English has a significant influence on Dutch youth language. Many role models for teens, such as film actors, musicians and personalities on television and the Internet, as well as trends and fashions, are from the U.S. and a great deal of neologisms are the result of that.[58] Stenström and Jørgensen also claim that 'youngsters whose native language is not English tend to adopt English words and expressions'.[59] They refer to Catalá Torres, 'who adds that such borrowings sometimes adapt to the syntax of the receiving language'.[60] They also support Hoppenbrouwers' conclusion that this is particularly true for 'topics such as romance and sex, partying and drinking, the body, hobbies' – in other words: 'What the youngsters talk about obviously has an effect on their vocabulary'.[61] Loans like 'mountainbiken' or 'I-padden' and calques such as 'zie je' ('see you') and 'hoe goed/vreemd/etc. is dat!' (how ... is that!') are examples of such neologisms in present Dutch. According to Hoppenbrouwers, subjects like the choice of education and future profession are influenced by parents, rather than friends, as is the language that is used to talk about those topics.[62]

[57] Cor Hoppenbrouwers, Jongerentaal: De Tipparade van de Omgangstaal (Hoogezand: Stubeg, 1991) 5.
[58] Hoppenbrouwers 5.
[59] Anna-Brita Stenström and Annette Myre Jørgensen, ed., Youngspeak in a Multilingual Perspective (Amsterdam and Philadelphia: John Benjamins Publishing Company, 2009) 3.
[60] Stenström and Jørgensen 3.
[61] Stenström and Jørgensen 3.
[62] Hoppenbrouwers 5.

On the one hand, young people do not like it if people outside their group, such as their parents, use their special vocabulary. Hence, it may not necessarily be a good decision to use youth language in books that have been written for teens by older people. *Marfan Syndrome: A Guide for Teens* has a clear pedagogical purpose, and the source text is not characterised by the use of youth language. On the other hand, many remarks in the sideline have been written by other teens, the photographs also depict young people and the teens are explicitly invited to contact other teens. The sole linguistic outreach towards the teens in the main text seems to be that the register of the ST is somewhat colloquial.

§ 3.6 | **Conclusion**

English and Dutch medical terminology have a shared history, so that terms are often very similar. However, that makes it even more important to remain aware of 'false friends'. The translator should always be extremely certain about the proper term in the target language, considering the influence of medical texts on patients. Nevertheless, the translator shoul not avoid the use of terminology. Medical terminology can be described as a type of specialist language, that requires specialist knowledge to be fully understood. They should be sensitive about the patient's capacity to understand what is said and if necessary, add an explanation. The level of terminology in a text differs per text type. Although *Marfan Syndrome: A Guide for Teens* does not contain much terminology (compared to professional medical texts, not to regular texts such as newspaper articles), the target group still requires the use of specific writing techniques for the TT to be easy to read and understand.That may even include stylistic adaptation of the ST, in the case of poor writing skills of the original author, according to rules such as Albin's. First and foremost, translating according to functionalist principles is about preservation of the message. As it may safely be assumed that poor language in the ST is no integral part of that message, a translator even has the obligation to critically assess the language quality of the ST, because poor language in the translation will actually disturb preservation of the message. In order te comply with the loyalty principles of Nord and the norms of Chesterman, the translator should discuss this with the commissioner of the translation. If a more structural change is involved, he may even have to consult the author of the ST. To a very limited extent, the TT can include the use of youth language, mostly in the form of quotations, in order to put its message across to the readers.

[Chapter Four]

Marfan Syndrome

§ 4.1 | **Marfan Syndrome**

As it was argued in chapter three of this thesis, the description of medical phenomena need to include the professional terminology and, if necessary, the meaning of this terminology in plain language. Below is a professional definition of Marfan syndrome, which is the only way to describe exactly what the syndrome is. After that comes an easier explanation of the disease, for the sake of intelligibility.

In technical terms, Marfan syndrome is an autosomal dominant mutation in the Fibrilline 1-gene on chromosome 15. [63] Besides, a patient must have at least three of the following characteristics before Marfan syndrome can be diagnosed:

- Aneurysm of the ascending aorta (which means that one of the body's most important veins has a weak spot and may break, which is potentially life-threatening)
- Lens luxation (the position of the lens is unstable, which may ultimately cause blindness and severe pain)
- Arachnodactyly (very long fingers)
- Dural ectasia (aching in the very low back, caused by an enlarged membrane around the lower spine)
- Pectus excavatum or pectus carinatum (deformity of the chest, either outward or inward). [64]

On its website, the National Marfan Foundation describes Marfan syndrome in simple words:

> 'Marfan syndrome is a disorder of the connective tissue. Connective tissue holds all parts of the body together and helps control how the body grows. Because connective tissue is found throughout the body, Marfan syndrome features can occur in many different parts of the body.
>
> Marfan syndrome features are most often found in the heart, blood vessels, bones, joints, and eyes. Sometimes the lungs and skin are also affected. Marfan syndrome does not affect intelligence.'[65]

[63] Mensengezondheid.infonu.nl. "Wat is het syndroom van Marfan," 3 Feb. 2008. *Mens en Gezondheid*. Web. 28 Jan. 2011.
[64] NL.Wikipedia.org."Syndroom van Marfan," 5 May 2011. *Wikipedia.* Web. 28 Jan. 2011.
[65] National Marfan Foundation. "About Marfan Syndrome, " 2011. *National Marfan Foundation*. Web. 28 Jan. 2011.

> ‘People can inherit Marfan syndrome, meaning that they get the mutation from a parent who has the disorder. This is the case in about 3 out of 4 people with Marfan syndrome. Other people have a spontaneous mutation, meaning that they are the first in their family to have Marfan syndrome. People with Marfan syndrome have a 50-50 chance of passing the mutation on each time they have a child.
>
> People are born with Marfan syndrome but may not notice any features until later in life. Marfan syndrome features can appear at any age, including in infants and young children. They may get worse as people age.’[66]
>
> ‘It is very important that people with Marfan syndrome get treatment and follow medical advice. One reason is that heart problems can cause sudden death if they are not treated. Early diagnosis means helpful treatment can begin early in life. Physical activity guidelines for people with Marfan syndrome should not play active team sports such as football, soccer, or basketball. They should not lift heavy objects when at work, home or the gym. With early diagnosis and appropriate management, the life expectancy for someone with the Marfan syndrome is similar to that of the average person.’[67]

These two different ways to describe Marfan illustrate the tension in a medical text for (young) patients. On the one hand, there should be a minimum level of detail. On the other hand, that level of detail is indispensable for the message to come across to the target group. This means that in translation of medical terms, more space is needed for the same contents (a distribution change, in terms of Chesterman’s strategies, to solve an intralingual pragmatic translation problem, along with explicitness change and innumerable syntactic changes, because the target text has not only a referential, but also an appellative function).

Typical Marfan patients will not be physically limited in performing daily tasks. However, they are advised not to participate in strenuous activities, such as sports and physical games, because of their weak aorta. Instead, they could study, learn to play an instrument, become a photographer, or find another non-physical strength to spend their leasure time and prepare for their professional future.

[66] National Marfan Foundation. “What Causes Marfan Syndrome,” 2011. *National Marfan Foundation*. Web. 28 Jan. 2011.
[67] National Marfan Foundation. “What to Expect,” 2011. *National Marfan Foundation*. Web. 28 Jan. 2011.

Patients with Marfan syndrome generally look different, as a result of their tall features, their possibly deformed chest and their strong glasses. Although they will feel some pain most of the time, they do not need to use wheel chairs. If patients with Marfan syndrome have a responsible lifestyle, their life expectancy is similar to anyone else's. An important part of the pain that a patient with Marfan syndrome feels is emotional, partly because of the way they look (and the extent to which they are accepted by others), partly by the questions they probably have about the hereditary and incurable nature of the disease.

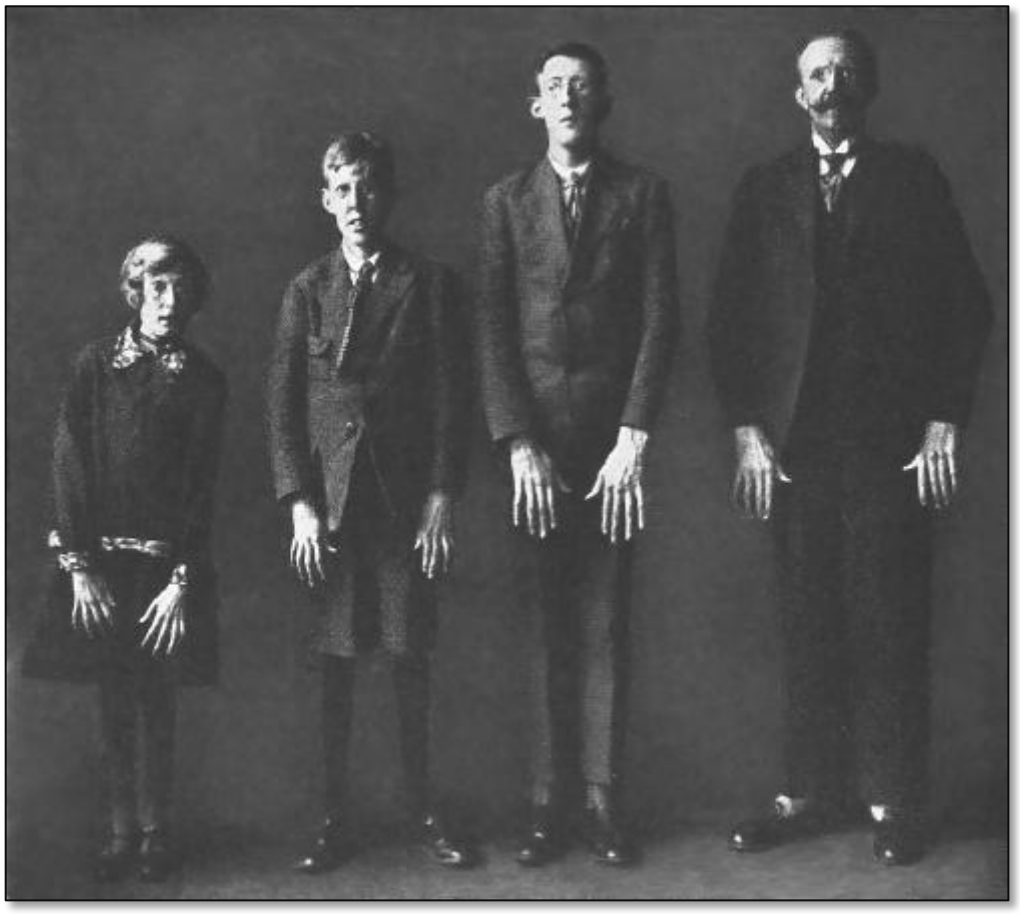


Image 1: Physical Marfan features in a family [68]

[68] Marfansyndrome.info. "A German Family in 1930 affected by Marfan Syndrome," 2006. *Marfansyndrome.* Web. 25 May, 2011.

§ 4.2 | **Marfan in the Netherlands**

In the Netherlands, '[a]bout 1 in 5,000 people have Marfan syndrome. This includes men and women of all races and ethnic groups'.[69] There are 16,681,753 Dutch[70], which means that 3,336 of them will statistically have Marfan syndrome. Their interest is mainly represented by the 'Contactgroep Marfan Nederland' (CMN). IN 2008, 600 -1,000 patients were actually involved with the CMN.[71] The CMN uses membership fees, a few donations and some government support as follows:

'The Contactgroep Marfan Nederland educates patients, relatives, students, specialists, general practitioners, schools, social institutions and the general public. The purpose of the education is:

- To give proper information about the course of the disease and the consequences of taking medication;
- To increase defensibility towards physicians and other healthcare professionals;
- To help relatives to understand problems and uncertainties with patients;
- To improve the quality of medical care and to increase direct recognition of the syndrome;
- To achieve more awareness of Marfan syndrome and consequently a greater understanding and acceptance of the (im)possibilities of the Marfan patient in society.

In order to achieve these goals, we make use of the following practical instruments:

- News letter "Marfinfo" and magazine "Hartezorg"
- Web site;
- Education of groups;
- Education during spring contact day;
- Publications.'[72]

The translation of *Marfan Syndrome: A Guide for Teens* has to relate to the commisioner's goals. That means the booklet should give information (its referential function), empower patients and their relatives (its appellative function), improve healthcare (its appellative function), and increase acceptance of Marfan syndrome in society (its appellative function). The expressive function of the text cannot be explicitly derived from the CMN's goals, yet it

[69] National Marfan Foundation. "About Marfan Syndrome, " 2011. *National Marfan Foundation*. Web. 28 Jan. 2011.
[70] Centraal Bureau voor de Statistiek. "Bevolkingsteller," 26- May 2011. *Centraal Bureau voor de Statistiek*. Web. 26 May 2011.
[71] Contactgroep Marfan Nederland. "Jaarverslag 2008 en vooruitblik 2009," 7 Mar. 2009. *Contactgroep Marfan Nederland*. Web. 3 Feb. 2011.
[72] Contactgroep Marfan Nederland. "Voorlichting en Publiciteit," 2010. *Contactgroep Marfan Nederland*. Web. 3 Feb. 2011.

is implicit that the NMF cares about Marfan patients: it is the very motive that drives them. It is not possible to found the phatic function of the TT on the commissioner's goals, since this particular function refers to expressions that only have a social function, such as 'Dear parents'. These expressions are present in the ST.

The other activities and publications of the NMF outline the context of the TT. If the ST refers to activities in the source culture, such as an annual meeting, these references can possibly be translated by mentioning the activities of the NMF, in order to preserve the referential and appellative functions of that fragment.

§ 4.3 | **Marfan in the United States of America**

Since the total number of American citizens was 308,745,538 in April 2010,[73] there are 61,749 American Marfan patients (according to Marfan statistics). As a result, there are tens of thousands of relatives and friends who have this disease in their direct environment. The National Marfan Foundation (NMF), that represents Marfan patients in the United States, is primarily dependent on 'individual contributions and special event fundraising efforts nationwide'[74]. Therefore, many donations come in to support the actions of the NMF: in 2009, they had an annual income of nearly 2 million US Dollars.[75] Through the IFMSO, the global network of Marfan syndrome organisations, the NMF have contact with the CMN (and with many other organisations worldwide) in order to share information and contacts.[76] The NMF have a great deal of knowledge to offer, both because of their considerable annual income and because important research into Marfan syndrome takes place in the United States. Hal Dietz is an influential Marfan researcher at the Institute of Genetic Medicine of Johns Hopkins University in Baltimore (MD), who is mentioned frequently on the NMF website.[77]

The NMF has the following Mission Statement:

'The National Marfan Foundation, founded in 1981, is a non-profit voluntary health organization dedicated to saving lives and improving the quality of life for individuals and families affected by Marfan syndrome and related disorders.'

[73] U.S. Census Bureau. "Population Density," 3 Feb. 2011. *United States Census 2010*. Web. 3 Feb. 2011.
[74] National Marfan Foundation. "Donate," 2011. *National Marfan Foundation.* Web. 3 Feb. 2011.
[75] National Marfan Foundation. "Financial Statements," 30 Jun. 2009. *National Marfan Foundation.* Web. 3 Feb. 2011.
[76] International Federation of Marfan Syndrome Organizations. "IFMSO Mission," 2005. *Marfanworld*. Web. 25 May 2011.
[77] Johns Hopkins Medicine. "Harry (Hal) Dietz, M.D.," 2011. *Johns Hopkins Medicine*. Web. 25 May 2011.

The Foundation accomplishes these goals through:

- **Research -** Promoting research to improve diagnosis and treatment and to find a cure
- **Education -** Providing accurate and up-to-date information about Marfan syndrome and related disorders to patients and families, health care professionals, and the general public
- **Support Services-**Helping individuals and families with Marfan syndrome and related disorders

Resources that the NMF use to achieve these goals include:

- The NMF Information and Resource Center
- The National Volunteer Network
- The NMF Annual Conference
- The NMF newsletter, Connective Issues
- The NMF website [78]

It is no surprise that the goals of the NMF are quite similar to those of the CMN: both organisations intend to educate and support patients with Marfan syndrome and their relatives, and both organisations want to improve health care for Marfan patients. On the other hand, the NMF promote research more prominently, and their resources include a contact center. On the whole, the result of this somewhat broader approach is that *Marfan Syndrome: A Guide for Teens* may contain references to research and resources that do not have a counterpart in the Netherlands. However, Dutch Marfan patients can benefit from direct references to medical research in the United States, albeit that this information is only available in English. In practice, important research results will be published on the CMN website in Dutch. Pragmatic translation problems can thus be resolved by using pragmatic strategies, such as cultural filtering (adapting culture specific elements from the ST to the target culture, or rather maintaining them in the TT as foreign elements).

§ 4.4 | **Teens with Marfan**

Since Marfan syndrome is a hereditary disease, children are born with it. The actual symptoms can start to emerge in any phase of life (as mentioned above), but there is quite a chance that many teens already have Marfan features. Besides this, children of parents with Marfan have a one in two chance to inherit the disorder, so they will want to know whether or not they have been affected, even if no features have appeared yet. Apart from those patients, there are also teens with Marfan due to a spontaneous cause. Being adolescent in Western society means asking questions about your identity, especially for people who inherited a disease that is potentially life-threatening and that has a great impact on lifestyle

[78] National Marfan Foundation. "Mission Statement," 2011. *National Marfan Foundation*. Web. 3 Feb. 2011.

and physical appearance of patients. Hence it is not a luxury that specific and accessible information for adolescents is available to support them.

In the Netherlands, the Contactgroep Marfan Nederland have dedicated a small part of their web site to children, but there is no part of the site that is especially for teens. The children section does contain some information for teens, but it has not been specifically labelled. Since 24% of the Dutch population is below 20 and Marfan patients have a similar life expectancy to other people, there will be ca. 833 Marfan patients in this age group.[79] If ca. 400 of them are between 10 and 20, this justifies the existence of some tailor made information, and it explains the client's request to translate *Marfan Syndrome: A Guide for Teens* into Dutch.

The website of the National Marfan Foundation in the United States of America has a 'children and teens' section, which offers two free booklets about Marfan syndrome (among which *Marfan Syndrome: A Guide for Teens)* and which contains a link to a special Teen Space, that compares itself to Facebook, Myspace, Friendster, Youtube and the blogosphere. There is an online community called NMFconnect and hyperlinks to NMF channels and fanpages on Facebook, Twitter and Youtube to perform this role. In addition to this, there are subpages offering profiles of other teens and staff members with Marfan, fashion for long legs and other Marfan features, information on the NMF National Conference, and Q&A's to answer social and medical questions.[80] Given the international nature of online media, these possibilities are available for Dutch patients as well, to the extent that they understand English.

In general, the lives of adolescents in The Netherlands and in the United States are quite similar, especially since the rise of mass media and the Internet, as was argued in chapter three of this thesis. In both cultures, this is an age at which Marfan patients are confronted with a great deal of questions about their disease. This means that on the whole, the intended pragmatic function of the TT can be achieved without many pragmatic translation strategies. One example of a difference that does require such a strategy is the health insurance in the Netherlands, which is somewhat different from the USA. In the booklet, teens with Marfan are specificallt instructed to prepare for a job that includes healthcare benefits. This is less applicable in the Netherlands.

[79] NL.wikipedia.org. "Bevolking van Nederland," 9 Feb. 2011. *Wikipedia.* Web. 9 Feb. 2011.
[80] National Marfan Foundation. "Teenspace," 2011. *National Marfan Foundation*. Web. 9 Feb. 2011.

§ 4.5 | **Conclusion**

Marfan syndrome has many aspects, which vary from medical to social. The referential aspect of *Marfan Syndrome: A Guide for Teens* (the way it refers to phenomena in the world, such as Marfan syndrome and its consequences) must therefore be described in terms that are technical and precise, and in terms that are accessible and empathetic. From the description of the source culture and the target culture in this chapter it turns out that the CMN and the NMF have very similar objectives: to educate, to improve lives and to further knowledge about Marfan syndrome. The greatest differences between the source text and the target text are those differences that arise from the text itself. How does the text express the author's attitude towards its subject matter? How does it appeal to the receivers feelings and knowledge? How does it establish contact with its readers? Those questions will be discussed in the next chapters.

[Chapter Five]

Translation Analysis

§ 5.1 | Introduction

Nord's model prescribes that the Target Text be analysed prior to the Source Text. Therefore, paragraph 5.2 will be a Target Text analysis, based on Nord's question about the function, sender, addressee, medium, time and place of reception, motive, contents, non-verbal elements, words, sentences, tone and effect of the TT. Paragraph 5.3 will be a similar analysis of the Source Text. Paragraph 5.4 will subsequently be a comparison of the TT and ST analyses, and an inventarisation of translation problems that arise from this comparison, based upon Nord's hierarchy of translation problems as described in paragraph 2.3 of this thesis. The translator's footnotes in Appendix 1 will include the consequences of this analysis and the types of translation problems according to Nord's categorisation, as well as the required solutions to these problems and the motivation for the selected solutions, according to Chesterman's norms and strategies.

§ 5.2 | Target Text Analysis

The Contactgroep Marfan Nederland (CMN) has commissioned the integral translation of *Marfan Syndrome: A Guide for Teens* in 2006, specifically to address teens with Marfan and their parents, but secondarily also their siblings, physicians and caregivers, and Dutch society as a whole. The text will be published as a booklet that will be sold or freely distributed through the CMN website and at CMN events. The CMN's motive for this assignment is to fill a gap in the information they presently offer. More generally speaking, their motive is to inform, to coach, to convince and to connect.

The Target Text should be a full translation of *Marfan Syndrome: A Guide for Teens,* including practical information such as other interesting books and web sites, addresses of shops with special clothes and the pictures that are included in the book. The Target Text should be written in an optimal combination of complete, correct and accessible Dutch language, at an informal, friendly tone. The effect of the Target Text should be that Dutch teens with Marfan and everyone around them be better informed about Marfan syndrome, its consequences and the way to deal with it.

The Target Text has a *referential* function because it is meant to inform patients and their relatives, friends, physicians and caregivers, as well as society in general about the properties and consequences of Marfan syndrome, as stated in the Mission Statement of the

Contactgroep Marfan Nederland. Besides that, the text is also meant as an instruction for those groups how to deal with Marfan patients.

The Target Text has an *expressive* function because the CMN feels strongly about the way Marfan syndrome and Marfan patients are dealt with. The CMN asked for an integral translation of the booklet, including its introduction, afterword and images. These parts of the booklet will express a strong affinity of the CMN with their patients, which is after all the very purpose of the organisation. The Mission Statement of the CMN also expresses how they are involved with the situation of Marfan patients in the Netherlands.

The Target Text has an *appellative* function because it has to appeal to the way teens with Marfan look at themselves and to the way others look at teens with Marfan syndrome. Teens are expected to deal properly with their health, to talk about their disorder and society is expected to be understanding. Physicians are expected to recognise Marfan syndrome symptoms and to give the proper therapies and medication, as the CMN claim in their mission statement.

The Target Text also has a *phatic* function because the text will be fully translated, including the introductions and greetings. Besides this, it is part of the CMN's intention with this text to establish and maintain contact with teens and their families. As their name implies, they are a contact group, which means that they have and facilitate contact with and between Marfan patients. In that sense, the phatic function overlaps with the expressive function, but certain parts of the text will particularly be phatic.

All four functions of the Target Text are indispensable: leaving one out will erase a crucial aspect of the message and the intended effect. The main functions of the Target Text will be its referential and its appellative functions, because those are the aspects in which the Target Text can provide in filling the gap in the present information that the CMN offers. Yet, disregarding the expressive and phatic function will lead to a translation that does not fully match the mission statement of the CMN.

§ 5.3 | **Source Text Analysis**

Marfan Syndrome: A Guide for Teens has been written a the request of the National Marfan Foundation, with specific support from The American Legion Child Welfare Foundation and was published in 2006. The Source Text was published as a small booklet, including an insert for parents. The booklet has been published in The United States of America. The NMF are active to supprt Americans, although their web site also has a page for Marfan patients outside the USA. That page mainly serves as a link to other local Marfan organisations.

The booklet is directed at teens who have Marfan syndrome, their parents and other caregivers. The motive for the publication of the Source Text is for teens to get information

about Marfan syndrome, to find recognition with others, to become more assertive, to accept a certain lifestyle, and for parents to 'serve as a starting point for talking with [their] teen about what it means to have Marfan syndrome'. In a broader sense, it has been written for the general public, as stated in the Mission Statement of the NMF.

Marfan Syndrome: A Guide for Teens contains informations about the nature of Marfan Syndrome, the way it is diagnosed and treated, how to live a great life with Marfan syndrome, how to prepare for future things, such as health insurance, jobs, having children, and how to participate in the Marfan community. The book is direct and does not evade sensitive topics, but rather takes them head-on. On the other hand, because it has been written for teens, it only goes into a certain level of detail, although it does offer suggestions for further reading, including professional scientific and medical texts.

The photographs make up a crucial part of the booklet, because it has been added at the request of teens with Marfan, who were interviewed at a Marfan conference. The text has been written in an informal style, somewhat directive. The intended effect of the Source Text is that teens with Marfan have a certainty in their behaviour, that physicians can recognise Marfan symptoms and that relatives know what Marfan is and how they should deal with Marfan patients.

The Source Text has a *referential function* because, according to the teen's introduction, '[t]his booklet is designed to give you some of the answers you need [about having Marfan syndrome]. It also contains several instructions on ways for teens to deal with their disease.

The Source Text has an e*xpressive* function because the NMF is the third person plural in the booklet: 'We hope [the information] will help you as you take on more and more responsability'. In the final chapter of the booklet, they tell about their community, which is very useful, because '[y]ou can benefit from others'experiences and people everywhere can benefit from yours'. There is a very strong vision behind the publication of this booklet.

The Source Text has an *appellative* function because the NMF encourages parents and teens themselves to contact the NMF resources at many places in the booklet. Most of the booklet consists of very strong encouragements to have a responsible lifestyle, to take other precautions for a pleasant future and for parents, teachers and medical staff to deal properly with a teen who has Marfan.

The Source Text has a *phatic* function because it 'serves as [the] first introduction to a special community [of] supportive and caring people'. Apart from this booklet, the NMF offer many possibilities for Marfan patients to connect to other patients and staff members on their website, through which the NMF fulfils a key role in these contacts.

Similar to the Target Text, the referential and the appellative function define the central elements of the booklet, but the entire text is laced with elements that show its expressive

and phatic functions. These latter two functions occur most prominently, though, in the introductions, the afterword, and the photographs.

§ 5.4 | Translation Problems in *Teens with Marfan*

§ 5.4.1 | Pragmatic translation problems

In the Source Text, the pragmatic function is achieved through the use of American realia, such as photographs, interviews with famous (American) role models, and reference to (American) institutions, books and web sites. This means that certain (pragmatic) strategies will have to be applied in order to attain the same hierarchy of functions in the Target Text as in the Source Text, such as the inclusion of Dutch phone numbers (cultural filtering / information change) and the remark that this booklet originates from an American context, for example in the list of resources (visibility change).

§ 5.4.2 | Intercultural Translation problems

An example of a CTP is the use of medical terminology and maybe even the use of medication itself. On page 33 of *Marfan Syndrome: A Guide for Teens*, the author states that '[t]he blood-thinning drug Coumadin may cause birth defects, especially in the first trimester, and should be changed during pregnancy'. In the Netherlands, Coumadin (a brand name of the drug Warfarin) is not a registered anticoagulant.[81] Instead, doctors prescribe Marcoumar and SintromMitis.[82] However, because these drugs are dangerous to the fetus, doctors prescribe heparin during pregnancy.[83] Therefore, a functional and loyal translation of this text would be '[d]e bloedverdunnende medicijnen Marcoumar en SintromMitis kunnen aangeboren afwijkingen veroorzaken. Het is daarom verstandig om tijdens de zwangerschap tijdelijk over te stappen op heparine', applying strategies such as cultural filtering and explicitation, and consequently also syntactic and semantic strategies such as unit shift, clause structure change and distribution change (both expansion and compression).

[81] NL.Wikipedia.org. "Warfarine,"18 Nov. 2010. *Wikipedia*. Web. 5 Feb. 2011.
[82] Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie. "Marcoumar," 15 Jan. 2010. *Apotheek.nl*. Web. 5 Feb. 2011.
[83] Universitair Medisch Centrum Groningen. "Hematologieprotocollen," 2011. *Hematologie Groningen*. Web. 5 Feb. 2011.

§ 5.4.3 | Interlingual Translation Problems

An example of LTP is that English sentences tend to have the main verb of the subordinate clause immediately after the subject, whereas in Dutch, this verb would typically be located at the end of the clause. The functional Dutch translation of the sentence 'Many children feel angry at the parent from whom they inherited Marfan syndrome' would be 'Veel kinderen zijn boos op de ouder van wie ze het syndroom van Marfan hebben geërfd'. In this translation, the main verb 'inherited' has moved to the end, according to the phrase structure change strategy.

§ 5.4.4 | Text-specific Translation Problems

The ST of *Marfan for Teens* contains some examples of idiomatic language and puns, sometimes with the word 'Marfan' involved, such as 'Marfact´. Since there are no Dutch words that are semantically related to 'fact' and that start with 'fa',this will require strategies like scheme change, in combination with a compensation[84] elsewehere in the text to preserve the phatic function of the pun.

§ 5.5 | Conclusion

The first question to be considered was the translation type of the assignment that is the subject of this thesis. Because the Target Text must have a referential, expressive, appellative and phatic function, rather than a metatextual function, the translation of *Marfan Syndrome: A Guide for Teens* as assigned by the Contactgroep Marfan Nederland is an instrumental translation, more precisely an equifunctional translation, since the function of the target text is the same as that of the original text. Nevertheless, in order to create a functional and loyal translation, the text has to be adapted for a Dutch audience, which gives rise to the pragmatic, intercultural, interlingual and text-specific translation problems that were described in the previous section of this chapter for the overall level of the text. Those problems can be solved by the use of (a combination of) syntactic, semantic and pragmatic translation strategies, motivated by functional norms such as the desire to conform to the 'expectancy norms of the target-language community', the 'accountability norm', the 'communication norm' and 'the relation norm'.[85] The translation in chapter six of this thesis reflects the detailed translation problems and the suitable translation strategies that were chosen to comply with those translation norms. Appendix 1 contains a detailed justification of those translation choices.

[84] Chesterman 115.
[85] Chesterman 113.

[Chapter Six]

Annotated Translation of *Marfan for Teens*

§ 6.1 | **Introductions**

§ 6.1.1 | Parents' Introduction

Dear Parents, The National Marfan Foundation is pleased to provide this booklet written for teens affected with Marfan syndrome. Although the booklet is written for teens, we encourage you to read it also. Perhaps it will serve as a starting point for talking with your teen about what it means to have Marfan syndrome. Before writing the booklet, we asked our teens at an NMF annual conference what they wanted in a booklet written just for them. At their request the booklet includes medical information, non-medical issues associated with the disorder, personal stories from other affected teens, and photographs. We have tried to cover the concerns the teens raised by providing specific, concrete information. While writing the booklet, a committee of teens, young adults, genetic counselors, and NMF staff reviewed it throughout its development.	Beste ouders, De Contactgroep Marfan[1] wil graag dit boekje aanbieden,[2] dat is geschreven voor jongeren[3] met het syndroom van Marfan[4]. Hoewel het boekje is gericht tot[5] jongeren, raden we u aan[6] om het zelf[7] ook te lezen. Mogelijk vormt het een goede aanleiding[8] om met uw zoon of dochter te praten over wat het betekent om het syndroom van Marfan te hebben.[9] De inhoud van dit boekje is gebaseerd op een aantal gesprekken met jongeren op een jaarlijkse bijeenkomst van Marfanpatiënten.Deze jongeren hebben verteld hoe een boekje, dat speciaal voor hen is geschreven, eruit zou moeten zien.[10] Op hun verzoek bevat het boekje medische informatie, niet-medische onderwerpen die samenhangen met het syndroom[11], persoonlijke verhalen van andere jongeren met Marfan en foto's. We hebben geprobeerd om op de vragen van de jongerenin te gaan met specifieke en concrete informatie. Een team van jongeren, jongvolwassenen, genetisch adviseurs en stafleden van NMF (*National Marfan Foundation,* De Amerikaanse Marfanstichting die dit boekje oorspronkelijk heeft uitgegeven)[12] heeft de totstandkoming van het boekje gedurende het hele schrijfproces met een kritische blik gevolgd. Ook de inhoud van de professionele

	Nederlandse vertaling van het boekje is zorgvuldig beoordeeld door Marfandeskundigen.[13]
Teens with Marfan syndrome have special needs to become adults able to manage their medical care. We hope this booklet will guide teens as they move from care directed by their parents to care directed by themselves. We hope teens will find comfort in knowing they are not alone and will find inspiration from those who have shared their stories with us.	Jongeren met het syndroom van Marfan hebben speciale begeleiding nodig[14] om volwassenen te worden die goed om kunnen gaan met de medische zorg voor zichzelf.[15] Wij hopen dat dit boekje jongeren kan ondersteunen bij het proces waarin de verantwoordelijkheid voor deze zorg steeds meer aan henzelf wordt toevertrouwd.[16] Wij hopen dat jongeren troost zullen putten uit het besef[17] dat ze er niet alleen voor staan[18] en dat ze zullen worden geïnspireerd[19] door de tieners[20] die hun verhaal met ons hebben gedeeld.
Marfan syndrome is a complex disorder that affects different people in different ways. As a result, all of the information in the booklet may not relate to your teen. You may need more information on topics specific to your teen's Marfan management. We encourage you to contact the NMF Resource Center at 1-800-8MARFAN ext. 26 (1-800-862-7326 ext. 26) or by email at support@marfan.org to request more information or discuss concerns not covered in the booklet.	Het syndroom van Marfan is een complexe stoornis[21] die verschillende mensen op verschillende manieren beïnvloedt[22]. Daardoor is het mogelijk dat niet alle informatie in dit boekje van toepassing is op uw kind[23]. Als u specifieke informatie nodig hebt over de manier waarop u moet omgaan met het syndroom van Marfan van uw kind[24], kunt u altijd contact opnemen met de Contactgroep Marfan Nederland. U kunt bellen naar 033 - 422 6546 of e-mailen naar contact@marfansyndroom.nl om meer informatie aan te vragen of om onderwerpen te bespreken die in het boekje niet aan de orde zijn gekomen.
Sincerely, The National Marfan Foundation	Met vriendelijke groet, Contactgroep Marfan Nederland[25]

§ 6.1.2 | Teens' Introduction

HAVING MARFAN SYNDROME CAN BE *a scary thing, whether you are newly diagnosed or have known about it for years. There are probably hundreds of thoughts, questions, and concerns rushing through your head. That is normal. This booklet is designed to give you some of the answers you need.*	HET SYNDROOM VAN MARFAN KAN *behoorlijk beangstigend zijn. Dat geldt net zo goed voor iemand die nog maar net de diagnose heeft gekregen als voor iemand die al jaren weet dat hij of zij het heeft.* [26] *Waarschijnlijk schieten er honderden gedachten, vragen en zorgen door je hoofd. Dat is normaal. Dit boekje is bedoeld om een aantal van de antwoorden te geven die jij nodig hebt.*
The booklet also serves as your first introduction to a special community. It is much easier to deal with questions and concerns when you are surrounded by supportive and caring people. A community, at its best, pushes you to achieve anything you dream of. You now have the opportunity to be a part of a community that can do just that.	*Dit boekje is ook bedoeld om je voor te stellen aan een speciale groep mensen. Het is veel makkelijker om met je vragen en zorgen om te gaan als er mensen zijn die je steunen en die achter je staan. Zo'n groep mensen kan jou zelfs*[27] *de kracht geven om je droom te bereiken, wat die droom ook is*[28]*. Je hebt nu de kans om deel te gaan uitmaken van een groep mensen*[29] *die dat voor je kan betekenen.*
You may also be feeling some very powerful emotions. As you will see from the comments from other teens in this booklet, these emotions are not uncommon. Many people in our community have come to realize that Marfan syndrome is a part of who they are. It is no more a part of them then anything else. That realization has helped many to live full lives despite any challenges that may arise.	*Misschien ervaar je ook sterke emoties. Aan de reacties van andere jongeren in dit boekje kun je zien dat je niet de enige bent met deze gevoelens. Veel mensen uit onze gemeenschap zijn gaan inzien dat het syndroom van Marfan maar een deel is van wie ze echt zijn. Marfan bepaalt dus niet hun hele identiteit.*[30] *Dat inzicht heeft veel van hen geholpen om een normaal leven te leiden, ondanks de uitdagingen die zich kunnen voordoen.*
In addition, this booklet will help connect you to some very valuable resources. There are so many different kinds of people who would love to talk to you. No matter what you may be facing, there are people who can give you information. Everyone, from doctors to your peers, is at your fingertips. Inside you will find information on how to connect to people in the Marfan community.	*Dit boekje helpt je bovendien om een paar heel waardevolle contacten te leggen. Er zijn allerlei verschillende soorten mensen die graag een keer met je willen praten. In welke situatie je ook zit, er is altijd iemand die jou informatie kan geven. Iedereen, van artsen tot leeftijdgenoten, is voor jou binnen handbereik. In dit boekje vind je informatie over de manier waarop je in contact kunt komen met deze mensen uit de Contactgroep Marfan.*

It is important to take the time to learn what you can. Ask what you need to ask, and talk to whom you need to talk. I hope this booklet is a helpful step in your Marfan education. *Ben Weisman, age 22* *NMF Conference Teen Group Leader*	*Het is belangrijk om rustig de tijd te nemen om te ontdekken wat er allemaal mogelijk is. Vraag gewoon alles wat je wilt vragen en spreek vooral iedereen aan die je graag gesproken wilt hebben.*[31] *Ik hoop dat dit boekje jou zal helpen om goed om te gaan met Marfan.*[32] *Ben Weisman (22 jaar oud)* *Jeugdgroepleider op de NMF-conferentie* De NMF is de Amerikaanse Marfanstichting, die dit boekje oorspronkelijk heeft uitgegeven.[33]

§ 6.2 | Chapter 2: What Is Marfan Syndrome?

§ 6.2.1 | Main Text

II. What Is Marfan Syndrome?	II. Wat Is het Syndroom van Marfan?
Marfan syndrome is a disorder of connective tissue. Connective tissue holds all parts of the body together (it is sometimes called "the glue that holds the body together"), and helps control how the body grows. Because connective tissue is found throughout the body, Marfan features can occur in many different body systems, including the heart, blood vessels, bones, joints, and eyes. Sometimes, the lung and skin are also affected. Marfan syndrome does not affect intelligence.	Het syndroom van Marfan is een afwijking aan het bindweefsel. Bindweefsel houdt alle delen van je lichaam bij elkaar (het wordt ook wel 'de lijm die je lichaam bij elkaar houdt' genoemd) en het helpt mee bij het bepalen hoe je[34] lichaam groeit. Omdat bindweefsel in je hele lijf aanwezig is, kunnen kenmerken van Marfan voorkomen in allerlei delen van je lichaam[35], zoals je hart, je bloedvaten, je botten, je gewrichten en je ogen. Soms tast Marfan ook de longen en de huid aan. Het syndroom van Marfan heeft geen effect[36] op je intelligentie.
What causes Marfan syndrome? Marfan syndrome is caused by a change (mutation) on a gene on chromosome 15 that tells the body how to make fibrillin-1 - a protein that is an important part of connective tissue. When this gene has a mutation, the fibrillin-1, and therefore the connective tissue, is abnormal. Having abnormal connective tissue creates various Marfan features and causes medical problems for people with Marfan syndrome.	**Wat is de oorzaak[37] van het syndroom van Marfan?** Het syndroom van Marfan wordt veroorzaakt door een verandering (mutatie) van een gen op chromosoom 15 dat aan je lichaam vertelt hoe fibrilline-1 gemaakt moet worden. Fibrilline-1 is een eiwit en het is een belangrijk onderdeel van je bindweefsel.[38] Als dit gen een mutatie heeft, dan is de fibrilline-1, en dus het bindweefsel, abnormaal. Abnormaal bindweefsel [39] zorgt voor diverse kenmerken van het syndroom van Marfan en het veroorzaakt medische problemen voor mensen die Marfan hebben.
About 3 out of 4 people with Marfan syndrome inherit their mutation from a parent who has the disorder. The remaining people with Marfan syndrome have a spontaneous mutation, meaning that they are the first in their family to have the disorder. No one knows why spontaneous mutations happen - there is nothing parents do or nothing in the environment that is known to cause a spontaneous mutation.	Ongeveer 3 van de 4 mensen met het syndroom van Marfan erven hun mutatie van een ouder die de ziekte zelf ook[40] heeft. De overige mensen met Marfan hebben een spontane mutatie, dat wil zeggen[41] dat ze de eerste in hun familie zijn met[42] deze ziekte. Niemand weet waarom spontane mutaties plaatsvinden – er is niets dat ouders doen en niets[43] in de buitenwereld waarvan we weten dat het een spontane mutatie veroorzaakt.

§ 6.2.2 | Teen Perspective

"When you find out you have Marfan syndrome, it's very easy to feel sorry for yourself and be scared for the future. I suggest taking the disorder head on. Find out as much as you can about what it is and how it can be treated. Find out your physical limitations and what you can still do without risking bodily harm." - Aaron	"Als je ontdekt dat je het syndroom van Marfan hebt, is het heel verleidelijk om medelijden te hebben met jezelf en om bang te zijn voor de toekomst. Je kunt beter de confrontatie met de ziekte frontaal aangaan[44]. Zoek zo goed mogelijk[45] uit wat Marfan[46] is en hoe het syndroom kan worden behandeld. Ontdek je lichamelijke grenzen en wat je nog wel kunt doen zonder verwondingen te riskeren." - Aaron

§ 6.2.3 | Marfacts

People with Marfan syndrome have a 1 out of 2 chance of passing the mutation on each time they have a child.	Mensen met het syndroom van Marfan hebben elke keer als ze een kind krijgen een kans van één op twee om de mutatie door te geven.

§ 6.2.4 | Helpful Hints

Learn the symptoms of retinal detachment and spontaneous pneumothorax. Neither is life-threatening, but both require immediate medical attention. Symptoms of retinal detachment may include: - flashing lights - new floaters (specks floating across your vision) - a gray curtain moving across your field of vision Symptoms of spontaneous pneumothorax may include:	Leer de symptomen van netvliesloslating (ablatio retinae) en een spontane klaplong (pneumothorax) uit je hoofd[47]. Deze problemen zijn niet levensbedreigend, maar voor beide heb je onmiddellijke medische hulp nodig[48]. Symptomen van netvliesloslating zijn bijvoorbeeld: • lichtflitsen[49] • nieuwe troebelingen (vlekjes die door je blikveld drijven) • een grijs gordijn dat over je blikveld schuift Symptomen van een spontane klaplong (pneumothorax) zijn bijvoorbeeld:

• shortness of breath • dry cough • sudden onset of chest pain that gets worse when you take a deep breath	• kortademigheid • een droge hoest • een plotseling opkomende pijn op je borst die erger wordt als je diep ademhaalt

§ 6.3 | Chapter 3: How Is Marfan Syndrome Diagnosed?

§ 6.3.1 | Main text

III. How Is Marfan Syndrome Diagnosed?	III. Hoe Wordt het Syndroom van Marfan Vastgesteld?
People may need several tests and appointments with various doctors before they can be diagnosed with Marfan syndrome. This is because Marfan syndrome is diagnosed on the basis of a thorough medical evaluation of different body systems. Doctors take the results of a person's medical history and all the tests and then use a special pre-determined list of Marfan syndrome features called "diagnostic criteria" to decide if a person has the disorder. The criteria require that a person have Marfan syndrome features in at least two different body systems if a parent or sibling has Marfan syndrome and in three different body systems if no one else in the family has Marfan syndrome. Using the criteria is complicated and even some doctors are not sure how to use them. A doctor who has had experience diagnosing and caring for people with Marfan syndrome is more likely to know how to use the criteria and make a correct diagnosis.	Er zijn[50] soms meerdere onderzoeken en meerdere doktersbezoeken nodig voordat kan worden vastgesteld dat iemand het syndroom van Marfan heeft. Dit komt doordat het syndroom van Marfan wordt vastgesteld op basis van grondige medische onderzoeken van verschillende delen van je lichaam. Dokters kijken naar iemands medische verleden en naar al die medische[51] onderzoeken. Dat combineren ze met een lijst met vooraf vastgestelde kenmerken van Marfan.[52] Die kenmerken worden 'diagnostische criteria' genoemd.Door die combinatie kunnen ze bepalen of iemand Marfan heeft.[53] Volgens deze diagnostische criteria moet iemand met een ouder, broer of zus die Marfan heeft, zelf in minstens twee delen van het lichaam kenmerken van Marfan hebben.[54] Als niemand anders in het gezin het syndroom van Marfan heeft, moet iemand in minstens drie delen van het lichaam kenmerken van Marfan hebben. Het is ingewikkeld om de criteria te toe te passen. Er zijn zelfs dokters die niet precies weten hoe de criteria moeten worden toegepast.[55] Een dokter die ervaring heeft met het vaststellen van het syndroom van Marfan en met het zorgen voor deze patiënten kan waarschijnlijk beter met de criteria omgaan en stelt waarschijnlijk een betere diagnose.

§ 6.3.2 | Marfacts

As of 2006, the diagnostic criteria are called the “Ghent Criteria,” named after the city in Belgium where the doctors met when they created them.	De diagnostische criteria worden sinds 2006 de ‘Gent-criteria’ genoemd, naar de stad in België waar deze criteria in dat jaar door artsen zijn vastgesteld[56].
Marfan syndrome affects an estimated 1 in 5000 men, women and children of all races and ethnic backgrounds.	Ongeveer 1 op de 5.000 mannen, vrouwen en kinderen, van elke huidskleur en met elke etnische achtergrond, heeft het syndroom van Marfan.[57]
Marfan researchers have developed “Marfan mice” to aid in the study of the disorder. These are mice where a mutated fibrillin-1 gene is added to their genetic material. The resulting mice have Marfan characteristics such as aortic dilation, long legs and feet, deformed spines and underdeveloped lungs.	Wetenschappers die onderzoek doen naar Marfan[58] hebben “Marfanmuizen” ontwikkeld, als hulpmiddel[59] bij het bestuderen van de ziekte. Er is een gemuteerd fibrilline-1-gen toegevoegd aan het genetisch material van deze muizen.[60] Daardoor[61] kregen de muizen kenmerken van Marfan, zoals aortaverwijding, lange benen en grote voeten[62], vervormde ruggengraten en onderontwikkelde longen.
Scientists are studying the relationship between a growth factor called TGF-beta, which controls how the body grows, and fibrillin-1 to find new drug treatments that might stop aortic dilation and control other Marfan medical problems.	Wetenschappers onderzoeken het verband tussen de groeifactor “TGF-bèta”, die bepaalt hoe het lichaam groeit, en fibrilline-1, om nieuwe medicijnen en behandelingen te vinden die aortaverwijding kunnen tegenhouden en die ook invloed hebben op andere aan Marfan gerelateerde medische problemen.[63]

§ 6.4 | Chapter 4: How Is Marfan Syndrome Treated?

§ 6.4.1 | Main Text

IV. How Is Marfan Syndrome Treated?	IV. Hoe Wordt het Syndroom van Marfan Behandeld?
Because Marfan syndrome affects more than one body system, to have proper care, a person will likely need to see several medical specialists. At different times in life, one may need one kind of specialist more than another. In addition to a "primary care physician"- a pediatrician, family doctor or internist who takes care of routine medical problems and helps coordinate all parts of medical care - the specialists who are important in the treatment of Marfan syndrome include:	Omdat het syndroom van Marfan meer dan één deel van je lichaam aantast, moet je[64] waarschijnlijk diverse medische specialisten bezoeken om de goede zorg te krijgen. Op verschillende momenten in je leven heb je misschien meer behoefte aan de ene soort specialist dan aan de andere. Naast een 'eerstelijnsarts' – een kinderarts, huisarts of internist die routineuze medische problemen afhandelt en helpt bij het coördineren van alle aspecten van je medische zorgverlening – zijn de volgende specialisten belangrijk bij het behandelen van het syndroom van Marfan:
On a regular basis: • a cardiologist for the heart • an orthopedist for the bones and joints • an ophthalmologists for the eyes • a geneticist to help with diagnosis and help coordinate care	**Op regelmatige basis:** • een cardioloog voor je hart • een orthopeed voor je botten en gewrichten • een oogarts voor oogafwijkingen[65] • een geneticus om te helpen bij de diagnose en bij het coördineren van je zorgverlening
Others may be necessary for some people: • an orthodontist for crowded teeth • a pulmonologist for lung problems	**Sommige mensen hebben misschien nog andere specialisten[66] nodig:** • een orthodontist voor te dicht op elkaar staande tanden[67] • een longarts voor problemen met je longen

§ 6.4.2 | Teen Perspective

"Surgery is scary and worrisome, but have confidence in the medical professionals who are responsible for you and faith in their training and expertise." - Micah	"Een operatie is eng en vervelend, maar vertrouw op de professionele artsen die verantwoordelijk voor je zijn en geloof in hun ervaring en hun vakkundigheid." - Micah
"Your mind is your worst enemy. Doing your best to quiet your mind is an important preparation for surgery. Always ask questions so you know what the doctors and nurses are doing. Understanding what they are doing, and more importantly why, can help ease your mind." - Aaron	"Je hoofd is je grootste vijand. Bij de voorbereiding op een operatie is het belangrijk om te proberen jezelf te kalmeren.[68] Stel altijd vragen, zodat je weet wat de dokters en verpleegkundigen aan het doen zijn. Als je begrijpt wat ze doen en, nog belangrijker, waarom ze dat doen, kan dat je helpen om rustig[69] te worden." - Aaron
"I was pretty nervous before the surgery, and the recovery room was pretty scary because of all the equipment. I was in a lot of pain, but I distinctly remember my parents putting their hands on me and it made me feel safe. I also remember seeing my little sister and thinking if they let her in I was either dead or doing fine, and I was pretty sure I wasn't dead." - Ben* *From Weisman, R. with Berman, MD, B. *Own Your Health: Choosing the Best from Alternative and Conventional Medicine*, 2003, Health Communication Inc.	"Ik was nogal zenuwachtig voor de operatie en de verkoeverkamer was best eng door alle apparatuur. Ik voelde veel pijn, maar ik herinner me nog heel goed dat mijn ouders hun handen op me legden en dat gaf me een veilig gevoel. Ik herinner me ook dat ik mijn kleine zusje zag en dat ik dacht: 'als ze haar hier binnen laten, ben ik dood, of het gaat juist goed met me'[70], en ik wist vrij zeker dat ik niet dood was." - Ben* *Uit Weisman, R. en Berman, MD, B. *Own your Health: Choosing the Best from Alternative and Conventional Medicine,* 2003, Health Communication Inc.[71]

§ 6.4.3 | Marfacts

The benefits of the advances in aortic surgery are most effective if aortic root surgery happens in a planned manner before there is a dissection.	De voordelen van de vooruitgang in aortachirurgie zijn het meest effectief als operaties aan de aortastam gecoördineerd plaatsvinden, voordat de aorta begint te scheuren (aortadissectie).

§ 6.4.4 | Helpful Hints

Know your medications, take responsibility for monitoring you doses, and be faithful about taking them - medications only work if you remember to take them.	Ken je medicijnen, neem je verantwoordelijkheid voor de juiste dosering en gebruik ze regelmatig – medicijnen werken alleen als je ze ook echt inneemt[72].
It is a good idea to wear a bracelet that can alert emergency medical personnel that you have Marfan syndrome. An organization called MedicAlert™ has bracelets in many styles, including a new sports band. They can be reached at www.medicalert.org or 888-633-4298.	Het is slim[73] om een polsbandje of horloge te dragen dat medisch personeel er in geval van nood op kan wijzen dat jij het syndroom van Marfan hebt. Het Witte Kruis heeft polsbandjes en horloges in verschillende soorten, waaronder een sportbandje. Je kunt ze bereiken op www.whitecrossfoundation.org/nl of op 070 - 311 0486.[74]
For help finding doctors, you can refer to the NMF website for NMF local contacts who can direct you to a Marfan-knowledgeable physician in your area. Or, you can contact the NMF Resource Center at 800-8-MARFAN, ext. 26.	Voor hulp bij het vinden van artsen kun je terecht op de website van de contactgroep Marfan.[75] Daar vind je gegevens van contactpersonen in jouw omgeving die je in contact kunnen brengen met een arts bij jou in de buurt die verstand heeft van Marfan.[76] Je kunt de contactgroep Marfan ook bellen op 033 - 422 6546.

§ 6.4.5 | Good Advice

Marfan syndrome features and medical problems can get worse as people age. The care you take now may help prevent problems in the future.	Kenmerken en medische problemen die bij het syndroom van Marfan horen, kunnen verergeren wanneer mensen ouder worden. Als je nú zorgvuldig met jezelf omgaat[77], kun je daarmee toekomstige[78] problemen voorkomen.
Many teens have friends who smoke, and it can be hard at times to say no when your friends are doing it. Because not smoking is especially important for people with Marfan syndrome, people will respect your right to say no, especially if you say it with confidence.	Veel jongeren hebben vrienden die roken, en het kan soms moeilijk zijn om nee te zeggen als je vrienden een sigaret opsteken[79]. Omdat het vooral voor mensen met Marfan belangrijk is om niet te roken, zullen mensen jouw recht om nee te zeggen respecteren, vooral als je het zelfverzekerd zegt.
It is important to have a primary care physician you can trust, and who will help and work with you to make sure all of your doctors are on the same page regarding your treatment.	Het is belangrijk om een eerstelijns arts te hebben die jij vertrouwt.[80] Die arts helpt jou en zorgt er samen met jou voor dat de verschillende dokters die jou behandelen[81] niet langs elkaar heen werken.[82]

Trust your instincts. If something doesn't feel right, get it checked out. You should never be embarrassed to ask for an additional test or get a second opinion from another doctor. It is your right, and is in your best interest.	Vertrouw op je intuïtie. Als iets niet goed voelt, laat daar dan naar kijken. Wees nooit te verlegen om te vragen om nog een extra onderzoek of om de mening van een andere arts (een 'second opinion'). Je hebt daar recht op, en het is in je eigen belang.

§ 6.4.6 | Text without Header

The need for aortic surgery is determined by: • the size of the aorta • how fast the aorta is growing • whether or not the aortic valve is leaking • family history of aortic dissection	Of aortachirurgie nodig is[83], hangt af van: • het formaat van de aorta • de snelheid[84] waarmee de aorta groeit • het wel of niet lekken van de aortaklep • de familiegeschiedenis voor aortadissectie

§ 6.5 | Chapter 5: Living with Marfan Syndrome

§ 6.5.1 | Main Text

V. Living with marfan Syndrome	V. Leven met het Syndroom van Marfan
Family Issues Having Marfan Syndrome affects not only the person with the disorder, but also the whole family. Each family member reacts differently to the news of a diagnosis and the ongoing issues. This is true in families with several affected people and when there is only one person with Marfan syndrome. Here are some emotional issues that often arise in families: • Many children feel angry at the parent from whom they inherited Marfan syndrome. Or, if a person has a spontaneous mutation, some may feel angry that the parents might have done something to cause the mutation. • An affected child may feel jealous of any brothers or sisters who do not have Marfan syndrome. • Unaffected children may feel jealous of the sibling with Marfan syndrome because that person gets extra attention. • An affected child may be upset by parents who share medical information with other family and friends without first asking the child if that is o.k.	**Gezinskwesties** Het syndroom van Marfan[85] heeft niet alleen gevolgen voor degene die de ziekte heeft[86], maar ook voor het gezin als geheel[87]. Ieder gezinslid reageert anders op het nieuws dat er Marfan is vastgesteld[88] en wat daar allemaal bij komt kijken. Dit geldt voor gezinnen waar meerdere mensen Marfan hebben en voor gezinnen waarin er maar één persoon is met het syndroom van Marfan.[89] Dit zijn een aantal emotionele kwesties die zich vaak voordoen in gezinnen: • Veel kinderen zijn boos op de ouder van wie ze het syndroom van Marfan hebben geërfd. Of, als iemand een spontane mutatie heeft, kan zo iemand boos zijn omdat de ouders misschien iets gedaan hebben dat de mutatie heeft veroorzaakt. • Een kind met Marfan kan jaloers zijn op broers of zussen die geen Marfan hebben. • Kinderen die geen Marfan hebben kunnen jaloers zijn op de broer of zus met Marfan omdat die meer aandacht krijgt. • Een kind met Marfan kan van streek raken door ouders die medische informatie delen met andere familieleden en vrienden zonder eerst aan het kind te vragen of dat goed is.

• A child may be angry if parents are overprotective or if they provide constant reminders about taking medications or limiting physical activity. • Parents may feel that they want to protect children from in-depth understanding of their condition. • Parents may become very upset about the diagnosis and have difficulty talking about and coping with Marfan syndrome.	• Een kind kan boos zijn als ouders te beschermend zijn of als ze hun kind[90] er continu aan herinneren medicijnen in te nemen of lichamelijke inspanning te beperken. • Ouders willen hun[91] kinderen soms beschermen tegen het besef van hun lichamelijke conditie.[92] • Ouders kunnen erg in de war raken door de diagnose en het moeilijk vinden[93] om over het syndroom van Marfan te praten en ermee om te gaan.[94]

§ 6.5.2 | Teen Perspective

"Marfan syndrome brings with it the entire gambit of emotions from tranquility to pain to anger to depression and back again. Marfan syndrome can cause any emotion at any time. Having a support team of family and friends is vital for those times when personal perspective is not enough." - Matt	"Het syndroom van Marfan brengt een heel scala[95] aan emoties met zich mee, van rust tot pijn tot woede tot neerslachtigheid en weer terug. Het syndroom van Marfan kan op elk ogenblik elke emotie veroorzaken. Het is van levensbelang om een groep familieleden en vrienden om je heen te hebben die je steunen[96] op de momenten waarop je eigen relativeringsvermogen niet genoeg is." - Matt
"Giving up sports is a big issue for many teens. Any time you are told you cannot do something for reasons outside of your control, it is a deep personal challenge. It is not the end of your life, even though it can feel that way. You may find new hidden talents or interest you didn't know you had. You may also be able to find a way to stay involved in a particular sport or activity, but in a different way; for example, as a writer, coach or broadcaster." - Ben	"Veel jongeren vinden het heel vervelend dat ze niet kunnen sporten[97]. Als je te horen krijgt dat je iets niet kunt doen vanwege een oorzaak die je niet kunt beïnvloeden,[98] is dat altijd[99] iets dat je moet leren accepteren.[100] Het is niet het einde van je leven, hoewel je het gevoel kunt hebben dat dit wel zo is.[101] Je kunt nieuwe, verborgen talenten of interesses ontdekken waarvan je niet eens wist dat je ze had. Misschien vind je ook een manier om betrokken te blijven bij een bepaalde sport of activiteit, maar in een andere vorm; bijvoorbeeld als schrijver, coach of verslaggever." - Ben

"Having Marfan syndrome may, in fact, help some people do activities better than others. For example, the long fingers that many people with Marfan syndrome have can be an advantage when playing certain musical instruments, like the piano or guitar." - Caitlyn	"Door het syndroom van Marfan zijn sommige mensen zelfs beter in bepaalde activiteiten dan anderen. De lange vingers die mensen met Marfan vaak hebben, kunnen bijvoorbeeld een voordeel zijn bij het spelen van bepaalde muziekinstrumenten, zoals piano of gitaar." - Caitlyn
"Even though I stick out like a sore thumb, it doesn't interfere with me going out with friends, having relationships, doing well in school and otherwise leading a busy life." - Micah	"Ook al val ik ontzettend op,[102] toch kan ik makkelijk[103] uitgaan met vrienden, relaties hebben, doe ik het goed op school en leid ik ook op andere manieren een druk leven." - Micah
"In middle school, for the first time in my life I had the experience of being excluded because of the way I looked and the back brace I wore. One kid made fun of me every time he could. Finally, I went to the guidance counselor who called both of us into a meeting where I pulled up my shirt and said, 'This is my brace,' and I explained why I had to wear it. Then I said, 'Do you have a problem with that?' He never bothered me again." - Ben* *From Weisman, R. with Berman, MD, B. *Own Your Health: Choosing the Best from Alternative and Conventional Medicine*, 2003, Health Communication Inc.	"In de brugklas[104] voelde[105] ik me voor de eerste keer in mijn leven buitengesloten vanwege mijn uiterlijk[106] en omdat ik een korset droeg. Er was één jongen die me elke keer uitlachte. Uiteindelijk stapte ik naar de vertrouwenspersoon, die ons allebei op gesprek liet komen.[107] Ik trok mijn shirt omhoog en zei: 'dit is mijn korset,' en ik legde uit waarom ik die moest dragen. Daarna zei ik: 'heb je daar een probleem mee?' Hij heeft me nooit meer lastiggevallen." - Ben* *Uit Weisman, R. en Berman, MD, B., *Own your Health: Choosing the Best from Alternative and Conventional Medicine,* 2003, Health Communication Inc.
"Don't panic! It's not as bad as you think! It's kind of reassuring to know there's a reason why you can't build muscle or why your skeleton is weird or why you are so tall." - Clare	"Geen[108] paniek! Het is niet zo erg als je denkt! Het is juist wel geruststellend om te weten dat er een reden is waarom je geen spierweefsel opbouwt of waarom je skelet raar is of waarom je zo lang bent." - Clare

"When I was younger and having to deal with surgeries and being different, I struggled emotionally. I never took my shirt off in public and hated te fact that I couldn't play sports. I realize what was holding me back was my mind. Today, I find those experiences empowering. While at times I still show a bit of a chip on my shoulder, I generally embrace being different. So many kids my age have very little to distinguish themselves from our peers and I am glad I have an interesting story to tell. I have no problem telling people about my condition, but I do it only when I feel like explaining it all, or think they might find it interesting. I feel Marfan syndrome is not some dirty little secret to hide. I think it's natural for people to wonder why we look a little different and I find it satisfying to be able to explain it to them." - Aaron	"Toen ik jonger was en moest omgaan met operaties en met mijn anders zijn, had ik het emotioneel moeilijk[109]. Ik trok in het openbaar nooit mijn shirt uit en ik baalde er ontzettend van dat ik niet kon sporten. Ik besef nu[110] dat het probleem toen tussen mijn oren zat[111]. Nu krijg ik juist kracht[112] door die ervaringen. Hoewel ik soms nog steeds een kort lontje heb,[113] ben ik over het algemeen tevreden[114] dat ik anders ben. De meeste jongeren van mijn leeftijd hebben bijna niets dat hen onderscheidt van andere jongeren en ik ben blij dat ik een interessant verhaal te vertellen heb. Ik heb er geen probleem mee om anderen te vertellen over mijn gezondheid, maar dat doe ik alleen als ik zin heb om het helemaal uit te leggen, of als ik het gevoel heb dat iemand het interessant vindt. Ik denk niet dat het syndroom van Marfan een soort vies geheimpje is waar je stiekem over moet doen. Ik denk dat het normaal is dat mensen zich afvragen waarom wij er een beetje anders uitzien en het geeft mij een prettig gevoel[115] als ik dat aan hen kan uitleggen." - Aaron
"For a long time I felt like Marfan syndrome was a burden, a hindrance that held me back, that made me stand out when I didn't want to. I came to realize that I had it completely backwards. I am different. Being different implies individuality. With Marfan syndrome came a sharp mind, determination, motivation to succeed, and, most of all, a different perspective." - Matt	"Ik heb het syndroom van Marfan lange tijd ervaren als een last, een hindernis die me tegenhield, die me liet opvallen terwijl ik dat niet wilde. Ik ging inzien dat het precies omgekeerd was[116]. Ik ben anders. Anders zijn betekent uniek zijn. Samen met het syndroom van Marfan kreeg ik ook een kritische houding[117], doorzettingsvermogen, de motivatie om te slagen en, vooral, een ander perspectief." - Matt

§ 6.5.3 | Helpful Hints

Taking your medications on schedule and keeping your physical activity within prescribed limits will show your parents that you are responsible and provide evidence they do not need to constantly remind you how to care for yourself.	Als je op tijd je medicijnen inneemt en je lichamelijke activiteiten binnen de voorgeschreven perken[118] houdt, laat je aan je ouders zien dat je verantwoord met jezelf kunt omgaan[119]. Dat is voor hen bewijs dat ze jou niet voortdurend hoeven te laten weten hoe je het beste voor jezelf kunt zorgen.
School officials need to know that Marfan syndrome is a manageable medical condition and that teenagers almost never have aortic dissections.	Schoolpersoneel moet beseffen dat het syndroom van Marfan een beheersbare medische omstandigheid is en dat jongeren vrijwel nooit een aortadissectie krijgen.
The two most important federal laws about schools' obligations for students with disabilities or special needs are Section 504 of the Rehabilitation Act of 1973, and the Individuals with Disabilities Education Act (IDEA). A provision of the IDEA requires the school to prepare an individualized education plan (IEP) for the student.	Er zijn een aantal belangrijke wetten over verplichtingen die scholen hebben ten opzichte van leerlingen met een handicap of met speciale behoeften. Dat zijn bijvoorbeeld artikel 85a van de Wet op het Voortgezet Onderwijs (de 'Rugzak') en het advies van de commissie-Maatstaf, over de toegankelijkheid van het hoger onderwijs voor studenten met een functiebeperking.[120]

§ 6.5.4 | Good Advice

Thinking about how your parents feel may help. For example, affected parents may feel guilty if their children also have Marfan syndrome. Be patient, and try to talk about these feelings.	Het kan helpen om je te realiseren hoe je ouders zich voelen. Ouders met Marfan kunnen zich bijvoorbeeld schuldig voelen als hun kinderen ook Marfan hebben. Wees geduldig en probeer over deze gevoelens te praten.
Roller coasters and other amusement park rides should be approached with caution. People react to these rides in different ways. To be safe, you should know your body and monitor your own response.	Ga voorzichtig om[121] met achtbanen en andere heftige pretparkattracties. Iedereen reageert hier anders op. Om hier veilig gebruik van te kunnen maken,[122] moet je je eigen lichaam goed kennen en je bewust zijn van je eigen reacties.

Find physical activities you can do your whole life. Focus on games of skill rather than speed or endurance.	Ga op zoek naar lichamelijke activiteiten die je je hele leven kunt blijven doen. Concentreer je vooral op sporten die een beroep doen op je vaardigheden en techniek en niet op snelheid of uithoudingsvermogen.[123]
Use what you have to your advantage. Be proud of the way you look and embrace your so-called “flaws”. It is those flaws that make you unique. Develop a style and flair all your own.	Gebruik dat wat je hebt in je voordeel. Wees trots op je uiterlijk [124] en omarm[125] je zogenaamde ‘zwakten’. Juist die zwakten maken je uniek. Vind je eigen manier van doen - wees helemaal jezelf.[126]

§ 6.6 | Chapter 6: Preparing for Your Future

§ 6.6.1 | Main Text

VI. Preparing for Your Future Having Marfan syndrome doesn’t change the usual questions about the future that teens have. Will I go to college? Will I get a job? What kind of work/career do I want to have? For everyone, it is a good idea to get the best education possible in order to have the most career opportunities. People with Marfan syndrome can work at most jobs with a few exceptions. Jobs involving heavy exertion or lifting, such as construction work or stocking shelves, are not safe because of the strain the exertion will put on the heart and aorta. In addition, training for the military, police or fire department is too strenuous, as are professional sports.	**VI. Voorbereiding [127] op Je Toekomst** Jongeren met het syndroom van Marfan hebben niet opeens hele andere vragen over de toekomst.[128] Zal ik gaan studeren?[129] Zal ik een baan krijgen? Wat voor soort werk / carrière wil ik? Het is altijd verstandig om een zo hoog mogelijke opleiding te volgen voor de beste carrièremogelijkheden. De meeste banen zijn geen probleem voor mensen met het syndroom van Marfan, maar er zijn een paar uitzonderingen. Banen waarbij je je lichamelijk erg moet inspannen of zwaar moet tillen,[130] zoals het werk in de bouw of het werken als vakkenvuller,[131] zijn niet veilig vanwege de belasting die deze inspanning oplevert voor je hart en je aorta. Daarnaast zijn opleidingen voor het leger, de politie of de brandweer te zwaar, net zoals beroepssporten.

Having medical insurance is very important because of the life-long need for medical follow-up and care. Medical Insurance coverage through a parent or through state coverage for children will end at some point. (The exact time depends upon each insurance plan and how long you remain in school.) It is a good idea to know ahead of time when the coverage will end so you can plan how to keep medical insurance. Getting health insurance if you are self-employed is often very expensive and sometimes not possible because of what insurance companies call a "pre-existing" medical condition, such as Marfan syndrome. The best way to have medical insurance is to find a job in a company large enough to offer Group benefits for all employees. It is against the law to exclude employees from the company's medical plan because of a medical problem. This may mean taking a less desirabler job because it comes with medical benefits.	Het is ontzettend belangrijk om een goede zorgverzekering te hebben, omdat je levenslang behoefte hebt aan medische controle en verzorging. Je bent maar tot je achttiende verzekerd via je ouders en hun basisverzekering dekt veel kosten, maar bekijk ook of je aanvullende verzekeringen nodig hebt, bijvoorbeeld voor de orthodontist. Zorg er in ieder geval voor dat je op tijd weet wat je wilt, zodat je de zorgverzekering goed kunt regelen. Bij veel zorgverzekeraars is het niet mogelijk om een aanvullende verzekering af te sluiten vanwege een 'vooraf bekende ziekte of beperking´, zoals verzekeringsmaatschappijen dat noemen. Daarmee bedoelen ze bijvoorbeeld het syndroom van Marfan. Op vergelijkingswebsites zoals Independer.nl kun je vaak selecteren of een verzekering je onvoorwaardelijk accepteert.[132]

§ 6.6.2 | Teen Perspective

"Marfan syndrome may put up walls and block off roads, but life is so full of opportunities that we have to find the open highways." - Micah	"Het syndroom van Marfan kan muren bouwen en wegen blokkeren, maar het leven is zo vol met mogelijkheden, dat we moeten zoeken naar de snelwegen die er ook zijn."[133] - Micah
"I learned very early on that I would never become a famous athlete. I learned that to succeed, I would have to get the best education possible." - Matt	"Ik had al jong begrepen dat ik nooit een beroemde sporter zou worden. Ik begreep dat ik zo hoog mogelijk opgeleid zou moeten worden om succesvol te kunnen zijn." - Matt

§ 6.6.3 | Marfacts

The blood-thinning drug Coumadin may cause birth defects, especially in the first trimester, and should be changed during pregnancy.	De bloedverdunnende medicijnen Marcoumar en SintromMitis kunnen aangeboren afwijkingen veroorzaken. Het is daarom verstandig om tijdens de zwangerschap tijdelijk over te stappen op heparine.[134]

§ 6.6.4 | Helpful Hints

To find a vocational rehabilitation program in your area, Google vocational rehabilitation and your state's name.	Om een baan te vinden waarbij je zo nodig begeleiding krijgt, kun op Google zoeken met de volgende termen: - UWV (Wajong) - bemiddelingsbureaus - Administratief dienstencentrum - re-integratie - minszw - kenniscentrum crossover[135]

§ 6.6.5 | Good Advice

Know your rights when looking for a job. For example, an employer is allowed to ask about your ability to do specific job functions, but may not ask during a job interview if you have a disability or medical condition.	Ken je rechten als je een baan zoekt. Ook al ben je verplicht om tegen een werkgever te zeggen dat je een lichamelijke beperking hebt, een werkgever mag je alleen afwijzen als hij kan aantonen dat je daardoor niet in staat bent om bepaalde taken uit te voeren die bij de baan horen.[136]

§ 6.7 | **Resources**

More information from the National Marfan Foundation:	**Meer publicaties van de Contactgroep Marfan Nederland:**
Website: www.marfan.org Information Resource Center: 1-800-8MARFAN (800-862-7326) ext. 26 or e-mail: support @marfan.org	Website: www.marfansyndroom.nl Meer informatie aanvragen: bel 033 - 422 6546 of stuur een e-mail naar contact@marfansyndroom.nl.[137]
Books: • *Marfan Syndrome: A Primer for Clinicians and Scientists*, edited by Peter N. Robinson and Maurice Godfrey. Publisher: Kluwer Academic/ Plenum Publishers, 2004. Abstract of the chapters are available free on-line at www.eurekah.com. Individual chapters can be purchased for $ 19 each and the entire book costs $ 135. As the title states, this is a book written for doctors and scientists. Although the language is complicated and technical, it discusses Marfan syndrome by each body system and also has chapters on Marfan biochemistry and current Marfan research.	**Boeken:** • *Leef je Droom*, Olaf Oosterman. Uitgever: Hollandia, 2006. Olaf Oosterman heeft zelf het syndroom van Marfan. Het boek gaat over zijn zeilreizen. Hij biedt jongeren met o.a. Marfan de mogelijkheid om als bemanningslid deel te nemen aan zeilwedstrijden. Meer informatie vindt je op www.leefjedroom.com. • *Marfan Syndrome: A Primer for Clinicians and Scientists*, onder redactie van Peter N. Robinson en Maurice Godfrey. Uitgever: Kluwer Academic/ Plenum Publishers, 2004. Op www.eurekah.com kun je gratis samenvattingen van de hoofdstukken downloaden. Losse hoofdstukken zijn voor $ 19 te koop en het volledige boek kost $ 135. Zoals de titel al aangeeft, is dit boek geschreven voor dokters en wetenschappers. Hoewel het taalgebruik gecompliceerd en technisch is, wordt het syndroom van Marfan per deel van je lichaam behandeld en bevat het boek ook hoofdstukken over huidig onderzoek naar Marfan en biochemische aspecten van Marfan.[138]

§ 6.8 | Glossary

Amblyopia: An imbalance of vision where one eye sees better than the other. If not corrected, the brain may stop registering vision from the weaker eye.	**Amblyopie:** Een disbalans in het zichtvermogen, waarbij het ene oog beter ziet dan het andere. Als dit niet wordt gecorrigeerd, kunnen de hersenen ophouden met het registreren van signalen vanuit het zwakkere oog.[139]
Aneurysm: A bulging or enlargement of an artery.	**Aneurisma**: Een uitstulping of vergroting van een ader.
Aorta: The large artery that carries blood from the heart to the rest of the body. When talking about the aorta, doctors often refer to different parts: The aortic root is the part closest to the heart, next comes the ascending aorta, the aortic arch, the descending aorta. The descending aorta is divided into the descending thoracic aorta (in the chest) and abdominal aorta (below the diaphragm).	**Aorta:** De grote ader die bloed vervoert van het hart naar de rest van het lichaam. Als dokters over de aorta praten, bedoelen ze vaak een bepaald onderdeel: De aortastam zit het dichtst bij het hart, daarna komen achtereenvolgens[140] de ascenderende aorta, de aortaboog en de descenderende aorta. De descenderende aorta bestaat uit de descenderende thoracale aorta (in de borstkas) en de abdominale aorta (onder het middenrif).

§ 6.9 | Bibliography

Cardiac Articles	Artikelen over Hartafwijkingen[141]
Treatment of Aortic Disease in Patients with Marfan Syndrome. Milewicz, D.M., Dietz, H.C., and Miller, D.C. *Circulation* (2005), 111, e150-e157.	**Treatment of Aortic Disease in Patients with Marfan Syndrome.** Milewicz, D.M., Dietz, H.C., and Miller, D.C. *Circulation* (2005), 111, e150-e157.[142]

§ 6.10 | Illustrations

The illustrations make up a very important part of the booklet in terms of space, they are a vital part of the phatic function, and they have been made part of the booklet on special request of the teens for whom it was made. Therefore, I would advise the NMF to preserve these images in the TT, either as they are or depicting Dutch teens, doctors and parents.

[List of Works Cited]

Primary Text

National Marfan Foundation. Marfan Syndrome: A Guide for Teens. Port Washington (NY): National Marfan Foundation, 2006.

Secondary Texts

Albin, Verónica. "Translating and Formatting Medical Texts for Patients with Low Literacy Skills." Translation and Medicine. Ed. Henry Fischbach. Amsterdam and Philadelphia: John Benjamins, 1998. 117-130.

Brouwers, Lucas. "Digitaal doorvlooien." NRC Handelsblad. 15 Jan. 2011, Wetenschap: 10.

Chesterman, Andrew. Memes of Translation. Amsterdam/Philadelphia: John Benjamins Publishing Company, 1997.

Cicero, Marcus T. "De optimo genere oratorum." Introducing Translation Studies. Jeremy Munday. London and New York: Routledge, 2001. 19.

Gentzler, Edwin. Contemporary Translation Studies. New York: Multilingual Matters Ltd., 2001.

Hoppenbrouwers, Cor. Jongerentaal: de Tipparade van de Omgangstaal. Hoogezand: Stubeg, 1991.

Kenny, Dorothy. "Equivalence." Routledge Encyclopedia of Translation Studies. 1st ed. Ed. Mona Baker. London and New York: Routledge, 2001. 77-80.

Lankamp, Robert. "A non-specialist approach to defining medical language." Dutch Working Papers in English Language and Linguistics. Leiden: Rijksuniversiteit te Leiden, 1998.

Mason, Ian. “Communicative/ functional approaches.” Routledge Encyclopedia of Translation Studies. 1st ed. Ed. Mona Baker. London and New York: Routledge, 2001. 29-33.

McMorrow, Leon. “Breaking the Greco-Roman Mold in Medical Writing: The Many Languages of 20th Century Medicine.” Translation and Medicine. Ed. Henry Fischbach. Amsterdam and Philadelphia: John Benjamins, 1998. 13-28.

Montalt Resurrecció, Vicent. and María González Davies. Medical Translation Step by Step: Learning by Drafting. Manchester, UK and Kinderhook (NY), USA: St. Jerome Publishing, 2007.

Nida, Eugene. “Toward a science of translating.” Introducing Translation Studies. Jeremy Munday. London and New York: Routledge, 2001. 42.

Nord, Christiane. “Tekstanalyse en de moeilijkheidsgraad van een vertaling.” Denken over Vertalen. Tekstboek Vertaalwetenschap. 1st ed. Ed. Ton Naaijkens, Cees Koster, Henri Bloemen and Caroline Meijer. Trans. Cornelie van Rinsum and Henri Bloemen. Nijmegen: Vantilt, 2004. 235-242.

Nord, Christiane. “A Functional Typology of Translation.” Text Typology and Translation. Ed. Anna Trosborg. 26. (1997): 43-66.

Picht, Heribert and Jennifer Draskau. “Terminology: An Introduction.” A non-specialist approach to defining medical language. Robert Lankamp. Leiden: Rijksuniversiteit te Leiden, 1988. 4.

Pilegaard, Morten. “Translation of Medical Research Articles.” Text Typology and Translation. Ed. Anna Trosborg. 26. (1997): 159-184.

Sauer, Christoph. “Vaktaalkennis.” Metaphors in Moderd Medicine. Dineke van Vliet. Utrecht: Universiteit Utrecht, 1994. 5.

Schäffner, Christina. “*Skopos* Theory.” Routledge Encyclopedia of Translation Studies. 1st ed. Ed. Mona Baker. London and New York: Routledge, 2001. 235-238.

Stenström, Anna Brita and Annette Myre Jørgensen. Youngspeak in a Multillingual Perspective. Amsterdam and Philadelphia: John Benjamins, 2009.

Teunissen, Mariëtte and Geert Jacobs. “Oh, U bedoelt dat ik een hoge bloeddruk heb: over het uitleggen van medische vaktermen in arts-patiëntgesprekken.” Over de grenzen van de taalbeheersing. Taal, tekst en communicatie. Ed. Rob Neutelings, Nicole Ummelen and Alfons Maes. Den Haag: 2000. 427-439.

Web Sites

Centraal Bureau voor de Statistiek. “Bevolkingsteller,” 26- May 2011. *Centraal Bureau voor de Statistiek*. Web. 26 May 2011.

Contactgroep Marfan Nederland. “De Contactgroep Marfan Nederland,” 2010. *Marfansyndroom*. Web. 15 Jan. 2011.

Contactgroep Marfan Nederland. “Jaarverslag 2008 en vooruitblik 2009,” 7 Mar. 2009. *Contactgroep Marfan Nederland*. Web. 3 Feb. 2011.

Contactgroep Marfan Nederland. “Voorlichting en Publiciteit,” 2010. *Contactgroep Marfan Nederland*. Web. 3 Feb. 2011.

EN.Wikipedia.org. “Italian musical terms used in English,” 10 May 2011. *Wikipedia*. Web. 24 May 2011.

International Federation of Marfan Syndrome Organizations. “IFMSO Mission,” 2005. *Marfanworld*. Web. 25 May 2011.

Johns Hopkins Medicine. “Harry (Hal) Dietz, M.D.,” 2011. *Johns Hopkins Medicine*. Web. 25 May 2011.

Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie. “Marcoumar,” 15 Jan. 2010. *Apotheek.nl*. Web. 5 Feb. 2011.

Marfansyndrome.info. “A German Family in 1930 affected by Marfan Syndrome,” 2006. *Marfansyndrome.* Web. 25 May, 2011.

Mens en Gezondheid.infonu.nl. “Wat is het syndroom van Marfan,” 3 Feb. 2008. *Mens en Gezondheid*. Web. 28 Jan. 2011.

National Marfan Foundation. “About Marfan Syndrome, ” 2011. *National Marfan Foundation*. Web. 28 Jan. 2011.

National Marfan Foundation. “Financial Statements,” 30 Jun. 2009. *National Marfan Foundation.* Web. 3 Feb. 2011.

National Marfan Foundation. “Donate,” 2011. *National Marfan Foundation.* Web. 3 Feb. 2011.

National Marfan Foundation. “Mission Statement,” 2011. *National Marfan Foundation*. Web. 3 Feb. 2011.

National Marfan Foundation. “Teenspace,” 2011. *National Marfan Foundation*. Web. 9 Feb. 2011.

National Marfan Foundation. “What Causes Marfan Syndrome,” 2011. *National Marfan Foundation*. Web. 28 Jan. 2011.

National Marfan Foundation. “What to Expect,” 2011. *National Marfan Foundation*. Web. 28 Jan. 2011.

NL.Wikipedia.org. “Bevolking van Nederland,” 9 Feb. 2011. *Wikipedia.* Web. 9 Feb. 2011.

NL.Wikipedia.org. “Syndroom van Marfan,” 5 May 2011. *Wikipedia.* Web. 28 Jan. 2011.

NL.Wikipedia.org. “Warfarine,”18 Nov. 2010. *Wikipedia*. Web. 5 Feb. 2011.

Universitair Medisch Centrum Groningen. “Hematologieprotocollen,” 2011. *Hematologie Groningen*. Web. 5 Feb. 2011.

U.S. Census Bureau. “Population Density,” 3 Feb. 2011. *United States Census 2010*. Web. 3 Feb. 2011.

Cover Images

- Quest. “The Hands of a Marfan Patient,” Oct. 2004. *Quest Magazine*. Web. 9 Nov. 2010.

- National Academy of Sciences. “Organization of the fibrillin-1 molecule in microfibrils,” 2011. *Proceedings of the National Academy of Sciences.* Web. 9 Nov. 2010.

[Appendix 1]

Translation Notes

ad § 6.1.1 | Parents' Introduction

[1] The Dutch Marfan Foundation commissioned the translation of this booklet, in order to inform Dutch Marfan patients and their families. In order to solve this pragmatic translation problem and to comply with Chesterman´s norm of conforming to the expectancy of the target audience, the Dutch foundation should replace the original American foundation as the voice of this introduction. Later on in the parent's introduction, I make clear that the booklet was originally issued in America. That is necessary because of the intimate, coaching voice of this text. That operation is not part of Chesterman´s strategies, but he mentions it in paragraph 4.3.2 of *Memes of Translation* as a supplemental action, underlying his other strategies,in this case cultural filtering.

[2] In order to solve a syntactic interlingual translation problem in this phrase, the adverb 'graag' must replace the verb 'to be pleased', using transposition.

[3] The word 'teen' or 'teens' occurs very frequently in this text. I usually chose to translate this with 'jongere' instead of the more literal word 'tiener', because the former option is more common and more generic in Dutch. I used 'tiener', besides 'zoon of dochter' and tienerzoon of –dochter' as a translation for teen alternatively to make the text more pleasant to read (synonymy).

[4] A literal translation of 'affected' could be 'getroffen', but that really has a connotation of sudden events. to comply with loyalty norm, deletion of verb is best option. Words like 'dat is' and 'het' (before 'syndroom van Marfan') in this phrase must be inserted to solve interlingual translation problems: the sentence would be ungrammatical without them.

[5] I chose 'gericht' rather than 'geschreven', because the context (the next sentence) creates a contrast between this leaflet and the booklet itself: the leaflet is directed towards parents, while the booklet is directed towards teens. The word 'gericht' serves better to make this contrast explicit.

[6] The literal translation would be '…moedigen wij u aan', but that is an unusual formulation in this context. A better translation would be e.g. '…willen wij u aanmoedigen'. Yet I think 'aanraden' (to advise) is a better alternative, because it shows, rather than tells. It makes things more explicit. In that sense this translation choice is comparable to the choice in footnote 3.

[7] Without the insertion of 'zelf', a part of the appellative function would be lost.

[8] The literal translation would be 'beginpunt' or 'startpunt'. Although these words are proper Dutch, the word 'aanleiding' is more natural (and less of an Anglicism). This choice does change the sense of deictic direction, but it preserves the appellative function.

[9] Here, a change of distribution is required to solve an LTP. This change preserves the grammaticality of the text. Strictly speaking, this is within the boundaries of Chesterman's definition of a literal translation. The translation of 'teen' has been explained in footnote 3.

[10] In this section there is a PTP, that is related to the one described in footnote 1. The ST emphasises that the booklet has been composed after consulting people from the (American) target group. As a result, the text is tailor made to the TA of the ST. This has a phatic function, an expressive function, and a referential function. In order to preserve those functions, the TT should be constructed with the application of cultural filtering, information change (omission), distribution change, paraphrase, abstraction change, and change of temporal expression. The omitted information will be compensated at the end of this paragraph.

[11] The ST uses various terms to refer to Marfan syndrome, such as the shortened form 'Marfan' and the generic terms 'disorder' and 'syndrome', beside its full name, which obviously makes the text more interesting to read. A concordant translation would ignore the context and thus create an LTP. Instead, the TT should have its own set of alternative synonyms, to preserve the referential function of the text. On this specific location, 'syndroom' is more suitable than the literal translation 'stoornis' for semantic reasons.

[12] Here is the compensation that was referred to in footnote 1.

[13] In order to solve the PTP mentioned in footnote 1 and to preserve the expressive function, information change and cultural filtering are required.

[14] LTP must be solved with transposition: noun + adjective 'begeleiding nodig' replace noun 'needs'.

[15] Here, an LTP must be solved by using explicitation.

[16] This LTP must be solved with implicitation.

[17] This LTP must be solved with transposition: gerund 'knowing' is replaced by article + noun 'het besef'.

[18] This LTP must be solved by the insertion of rhetorical schemes 'troost putten uit' and 'er niet alleen voor staan', to preserve phatic and expressive function.

[19] This LTP must be solved by transposition: verb 'geïnspireerd' replaces noun 'inspiration'.

[20] This LTP must be solved by explicitation: 'tieners' instead of 'those'.

[21] In this case, 'stoornis' is a functional translation, because the sentence 'Het syndroom van Marfan is een complex syndroom' would not only be unelegant, but even change the meaning: it would suggest that in the next sentence, the author will state some

syndromes which are less complex than Marfan syndrome.

[22] LTP must be solved with schem change: preservation of repetition.

[23] To translate 'your teen' with 'uw jongere' (for reasons of consistency) would result in incorrect Dutch. There are two correct alternatives: 'uw tiener' (literal, but inconsistent) or 'uw kind' (more implicit, but age of child is clear from the context). Implicitation is preferable option, because it preservers phatic function more than 'tiener'.

[24] LTP must be solved with unit shift: the sentence must be split, to preserve readability of the TT.

[25] PTP must be solved with cultural filtering. This is comparable to the situation in footnote 1.

ad § 6.1.2 | Teens' Introduction

[26] In order to preserve the emphasis on 'Marfan syndrome' and the expressive function of this phrase, the name of the disease has to remain capitalised. That is why transposition is required to solve this LTP: the adverbial 'having Marfan syndrome' is replaced by the noun phrase 'het syndroom van Marfan'. However, this causes an interpersonal change: the reader is no longer directly addressed, but they become the third person. This needs to be compensated by distribution change. Transposition is also required because the literal translation of 'diagnosed' as a transitive verb would be 'diagnostiseren', which is too formal and would cause an unwelcome interpersonal change.

[27] In order to preserve the phatic function of this paragraph and solve an LTP, the English expression 'at its best' cannot be translated with the Dutch expression 'op zijn best', because that also implies a limit - 'only up to a point'. Therefore, a scheme change is required, by replacing 'at its best' by 'zelf', which has a similar semantic effect.

[28] To preserve the phatic function, the deleted scheme change must be compensated here in the shape of a repetition, by replacing 'anything' with 'wat die droom ook is' (a cohesion change).

[29] The term 'community' is a Dutch loan word, in the context of social networks. However, in the ST, the term refers to the NMF, and not specifically to its online activities. The term 'community' has more than one Dutch counterpart, such as 'gemeenschap', 'groep', 'groep mensen', or even 'Contactgroep Marfan'. In order to preserve the expressive function, I chose to use all of these options alternately.

[30] Here, the LTP requires a paraphrase. The semantic contents is not altered, and the compactness and energy of the translation make sure that the phatic and expressive function are preserved.

[31] An LTP requires a scheme change, which factually is the preservation of the scheme: the repetition of the imperative verbs ‘ask’ and ‘talk’ is preserved in the TT. That does involve distribution change, to preserve the strong appellative function.

[32] There is no literal translation for ‘Marfan education’ in Dutch.This LTP is solved by the use of transposition: the adjective + noun + preposition ‘helpful step in’ are replaced by the verb + adjective clause ‘helpen om goed om te gaan met’.

[33] This is another example of the PTP that was mentioned in footnote 1, and that is solved by the use of visibility change, distribution change, and information change.

ad § 6.2 | Chapter 2: What Is Marfan Syndrome?

[34] Throughout the ST, there are nouns without articles, especially when these sentences contain features of Marfan. In Dutch, there has to be either an article or a possessive pronoun. Using an article to solve this LTP would make the text less personal. In order to preserve the expressive function and prevent an unwelcome interpersonal change, possessive pronouns should be inserted. An exception can be made where the use of personal pronouns would have a somewhat ‘threatening’ effect, for example at the bottom of this paragraph.

[35] An LTP gives rise to an abstraction change, from body system to ‘deel van het lichaam’. The Dutch term ‘stelsel’, as it is used in ‘hart- en vaatstelsel’ would be the most suitable translation, but it cannot really be generalised to include all body systems.

[36] Here, an LTP is solved by transposition: the noun ‘effect’ replaces the verb ‘affect’.

[37] Here, another LTP is again solved by transposition: the noun ‘oorzaak’ replaces the verb ‘causes’.

[38] Because of English grammar, the noun ‘fibrillin-1’ is located at the end of the first clause. That makes it possible, and even stylistically required, to omit the repetition of this term in the second clause. This LTP must be solveb by the use of explicitation and unit shift.

[39] This LTP must be solved with transposition: the TT has a nominal clause instead of a verbal clause.

[40] The TT requires explicitation by adding the word ‘ook’, which preserves the emphasis. An alternative translation would be ‘... erven de mutatie van één van hun ouders’, but that would be an unnecessary distribution change.

[41] This LTP is another example of the way English gerunds cannot be translated directly into Dutch.

[42] Here, an LTP requires a transposition: the preposition ‘met’ replaces the verb ‘to have’.

[43] In order to preserve the expressive function of this sentence, the repetition in the ST must also be part of the TT. This must be achieved by applying distribution change.

[44] The ST contains a trope. This LTP can be preserved in the TT by using a similar trope. Apart from that, a change of explicitation is needed to solve another LTP: the first person singular is made implicit.

[45] In this situation, the appellative function of this imperative verb clause can be translated by applying distribution change: the TT denotes the same message with less words.

[46] The ST tends to use ‘it’ rather often as a kind of ellipsis, in this case to refer to Marfan. In Dutch, it is less common to use ‘het’ in that way. This LTP can be solved with explicitation, by mentioning the word ‘Marfan’ again. That also requires the use of ‘syndroom’ in the next sentence.

[47] This is an example of a cultural difference in the use of medical terminology. In the ST, medical terms are used to refer to a Marfan feature. However, in the TT, it is preferable to mention the medical term alongside the lay term. This CTP must therefore be solved by the use of double presentation.

[48] This LTP has to be solved with a clause structure change: the ST sentence has a different subject than the TT sentence.

[49] Here is an LTP that regularly occurs, as English has compounds in different occasions from Dutch. This problem has to be solved with transposition: the adjective + noun in the ST become a noun in the TT. The same happens in reverse order with ‘shortness of breath’ in this same paragraph.

ad § 6.3 | Chapter 3: How Is Marfan Syndrome Diagnosed?

[50] This phrase structure change is required because of the LTP that the transitive verb ‘to diagnose’ causes, as mentioned in footnote 27.

[51] In order to create a TT that is readable and accessible, this LTP must be solved by cohesion change, so ‘die’ has to be inserted.

[52] For the same reason as mentioned above, a coherence change is needed by inserting ‘daarnaast’. In the next sentences, the internal structure of the argumentation is also made more explicit by ‘die (criteria)’.

[53] In this fragment, the TL does not allow the compactness of the ST without loosing some if its referential function. therefore, a unit shift is needed, by splitting the ST sentence in more than one TT sentences. Apart from that, the verb ‘combineren’ replaces the plural noun ‘results’ (clause structure change).

[54] Because there is no literal translation in Dutch for the word ‘sibling’, this sentence in the ST has to become longer. Preserving the same sentence structure would make the argumentation unclear. To preserve the referential function, the sentence structure thus has to be changed.

[55] To preserve the referential function, a unit shift is needed here by splitting the sentence.

[56] This LTP requires implicitation: in the TT, the verb ‘named’ must be omitted to preserve elegance and to preserve the referential function. For the same reason, the verb ‘met’ is omitted. For the sake of cohesion, ‘dat jaar’ is inserted.

[57] Here, an LTP gives rise to the use of unit shift and distribution change: the TT sentence has a different subject.

[58] This LTP requires a distribution change and a clause structure change: the compound noun ‘Marfan researchers’ must be translated as a noun clause.

[59] This LTP requires a transposition: the verb ‘to aid’ must become the noun ‘hulpmiddel’.

[60] Here is another situation where an LTP gives rise to the use of unit shift and distribution change, so that the TT sentence needs to have a different subject.

[61] This LTP requires a transposition: the adjective ‘resulting’ must become the adverbial modifier ‘daardoor’.

[62] This LTP requires a distribution change, because the regular Dutch adjective for this meaning is ‘grote voeten’, rather than ‘lange voeten’.

[63] Here another LTP also requires a distribution change, because the ST is too compact to preserve its referential function in a literal translation.

ad § 6.4 | Chapter 4: How Is Marfan Syndrome Treated?

[64] Here, the LTP causes the use of an interpersonal change: in English, the use of an impersonal subject like ‘one’ or ‘a person’ is more common than in Dutch. In order to adapt the TT to TL norms, the best translation of ‘a person’ is je, but that makes the text somewhat more personal. Since the text has a phatic function, that should not be a problem.

[65] The translation of this sentence needs explicitation to fulfil its referential function; in a literal translation, there would almost be a pleonasm, due to the explicit nature of the word ‘oogarts’.

[66] The compact style of the ST sentence can only be preserved in the ST at the expense of the referential function. To preserve this function, explicitation is needed, which also causes a clause structure change (active instead of passive voice).

[67] In this case, an LTP gives rise to a trope change: the expression ‘crowded teeth’ does not have a Dutch equivalent. This distribution change does preserve the referential function.

[68] The English gerund causes a distribution change and a clause structure change.

[69] The trope ‘ease your mind’ cannot be translated into Dutch by a similar trope. In order to preserve the expressive function, it must be replaced by verbs and adverbial clauses such as ‘kalmeren’ and ‘rustig worden’.

[70] Here, explicitation and subtle transediting is needed to deal with an LTP, since in Dutch it is common to provide quotes with quotation marks and a colon.

[71] The reference to an English source results in a PTP. The referential function is best fulfilled by leaving this footnote as it is.

[72] In order to preserve its appellative function, this paragraph has to be translated with a little paraphrasing, creating a direct style in the TT.

[73] In order to preserve the appellative function of this phrase, the article + adjective + noun ‘a good idea’ has to be replaced by the adverb ‘slim’ (transposition).

[74] A CTP is caused because this paragraph refers to realia from the ST. In the Netherlands, there is a similar system to emergency bracelets, so the paragraph can be naturalised, to preserve its appellative and especially its referential function.

[75] Again, the appellative function of this text gives rise to a PTP, that must be solved with naturalisation.

[76] The adjective + noun + prepositional object ‘Marfan-knowledgeable physician in your area’ has to be translated as a noun + prepositional object + adjective clause ‘arts bij jou in de buurt die verstand heeft van Marfan’ (clause structure change).

[77] To preserve the coherence of this sentence and its appellative function, a transposition is needed: the noun ‘the care’ has to become the verb ‘omgaan met’.

[78] An LTP causes another transposition: the noun ‘future’ has to become the adjective ‘toekomstige’.

[79] As explained in footnote 46, explicitation of ‘it’ is needed here.

[80] Here, an LTP needs to be solved with a unit shift, by splitting the sentence.

[81] This LTP must be solved with a transposition: the noun ‘treatment’ is changed into the verb ‘behandelen’.

[82] The English trope ‘to be on the same page’ is preserved, by using the Dutch trope ‘langs elkaar heen werken’. That does require antonymy.

[83] An LTP has to be solved by transposition: the noun ‘need’ is replaced by the adjective ‘nodig’.

[84] Another LTP has to be solved by transposition as well: the adbverb ‘fast’ is replaced by the noun ‘snelheid’.

§ 6.5 | Chapter 5: Living with Marfan Syndrome

[85] This gerund causes an LTP, that must be solved with unit shift: the verb clause ‘Having Marfan syndrome’ becomes the compound noun ‘Het syndroom van Marfan’.

[86] This LTP gives rise to transposition, by inserting the verb ‘hebben’.

[87] This LTP is solved by transposition as well: the adjective ‘whole’ is replaced by the noun ‘geheel’.

[88] Here, explicitation is needed to preserve the referential function.

[89] This LTP is solved by distribution change, because the verb ‘affected’ cannot be translated literally into Dutch without affecting the referential function.

[90] Here, explicitation is needed because the transitive verb ‘herinneren’ requires an object.

[91] In this case, explicitation is needed to preserve the referential function.

[92] This LTP is solved by transposition: the verb ‘understanding’ is replaced by the noun ‘het besef’. The other change here involves explicitation: ‘condition’ is made more explicit in the TT, to preserve the referential function.

[93] This LTP is solved by transposition: the noun ‘difficulty’ is replaced by the adverb ‘moeilijk’.

[94] The Dutch verbs ‘praten’ and ‘omgaan’ require different prepositions, unlike the English verbs. That gives rise to distribution change.

[95] The English trope ‘the entire gambit of’ can be preserved by using the Dutch trope ‘een heel scala aan’.

[96] The gerund ‘having’ causes restructuring of the sentence in Dutch, and a transposition: the compound noun ‘support team’ is replaced by the noun + adjective clause ‘een groep ... die je steunen’.

[97] The gerund leads to transposition: the noun ‘sports’ becomes the verb ‘sporten’.

[98] This LTP must be solved with transposition: the noun ‘control’ is replaced by the verb ‘beïnvloeden’.

[99] This LTP must be solved with transposition as well: the noun ‘time’ is replaced by the adverb ‘altijd’.

[100] Here, explicitation is necessary, in combination with transposition. The noun ‘challenge’ is therefore replaced by the verb clause ‘leren accepteren’, to solve a CTP.

[101] This is another case of transposition, in combination with a distribution change: the verb ‘feel’ becomes the noun ‘het gevoel’.

[102] The English trope ‘stick out like a sore thumb’ does not have an equivalent in Dutch. Because the function is more important than the equivalence, the trope has to be dropped.

[103] This LTP causes antonymy: the ST has ‘it doesn’t interfere’, where the TT has ‘ik kan makkelijk uitgaan’.

[104] ‘Middle school’ is an American reale. to preserve the phatic function of this quotation, That CTP must be solved by using the Dutch reale ‘brugklas’.

[105] This LTP causes transposition: the noun ‘experience’ is replaced by the verb ‘voelen’.

[106] This LTP causes transposition as well: the verb phrase ‘the way I looked’ is replaced by the noun phrase ‘mijn uiterlijk’.

[107] Here, a unit shift is needed to preserve the phatic function: the sentence must be split to keep its point clear.

[108] This LTP leads to implicitation: In Dutch, the verb ‘hebben’ or ‘voelen’ is implicit.

[109] Here, transposition is needed: the verb ‘to struggle’ must be replaced by the verb phrase ‘het moeilijk hebben’.

[110] By adding words like ‘nu’ and ‘toen’, the coherence of this paragraph is emphasised, to support the phatic function.

[111] As a compensation for footnote 98, a trope is added here.

[112] This LTP causes transposition: the adjective ‘empowering’ becomes the noun ‘kracht’.

[113] The English trope ‘to have a chip on one’s shoulder’ can be preserved by using the Dutch trope ‘een kort lontje hebben’.

[114] This LTP also leads to transposition: the verb ‘to embrace’ can be replaced by using the adjective ‘tevreden’.

[115] This LTP causes transposition: the adjective ‘satisfying’ must be replaced by the noun phrase ‘een prettig gevoel’.

[116] This trope cannot be preserved in Dutch.

[117] An LTP causes implicitation: ‘a sharp mind’ is replaced by ‘een kritische houding’.

[118] To compensate footnote 117, a new trope can be added here.

[119] By splitting the sentence, the appellative function of this paragraph is displayed more clearly.

[120] A CTP arises because the text mentions USA legislation in a paragraph with an appellative function. Hence, the translation must mention comparable Dutch legislation.

[121] In this case, the appellative function is best preserved by using an imperative verb to apply clause structure change, when the sentence becomes active instead of passive.

[122] This idiomatic expression from U.S. English causes an LTP, which leads to a distribution change.

[123] Distribution change is needed to preserve the appellative function. The ST is extremely compact, but the TL does not allow a literal translation including the omission of the verb 'sporten' before (or after) 'uithoudingsvermogen'.

[124] In this case, the TL actually requires a more compact construction than the SL to preserve the appellative function. That also leads to transposition: the noun phrase 'the way you look' is replaced by the possessive pronoun + noun 'je uiterlijk'.

[125] 'Embrace' is used here as a metaphor. That metaphor can be preserved in the TT.

[126] Using the synonym 'je eigen manier van doen' for 'style' and flair' and applying a clause structure change are the best ways to preserve the appellative function.

ad § 6.6 | Chapter 6: Preparing for Your Future

[127] An LTP must be solved with transposition: the gerund verb 'preparing' needs to be replaced by the noun 'voorbereiding'.

[128] Another gerund leads to a clause structure change. The subject 'teens' is taken from its subclause and becomes (part of) the subject of the main clause.

[129] This LTP requires transposition: the noun 'college' has to be replaced by the verb 'studeren'.

[130] Distribution change is needed to preserve the referential and appellative function.

[131] The verb + noun structure 'stocking shelves' has to be replaced by the noun 'vakkenvuller'.

[132] This ST section refers to US health insurance, which is significantly different from health insurance in the Netherlands. That CTP must be solved with paraphrasing and naturalisation.

[133] These ST metaphors can be preserved in the TT.

[134] As mentioned in paragraph 5.4.2, this CTP requires cultural filtering and explicitation, and consequently also syntactic and semantic strategies such as unit shift, clause structure change and distribution change (both expansion and compression).

[135] This CTP requires naturalisation and distribution change to preserve its referential function.

[136] Also in this case, The TC situation differ from the SC situation, so that the text needs to be paraphrased and naturalised.

ad § 6.7 | Resources

[137] The address section obviously causes a PTP, that must be solved with naturalisation.

[138] The books section also causes a PTP, so that at least some Dutch books have to be part of it. The books in the source text may actually stay in the TT, because they do contain valuable information for TT readers who speak English, so that the referential function is preserved. The applicable strategies are visibility change and naturalisation.

ad § 6.8 | Glossary

[139] The addition of articles and verbs that the TL requires causes expansion.

[140] In order to support the referential function, the coherence of the TT must be made more explicit.

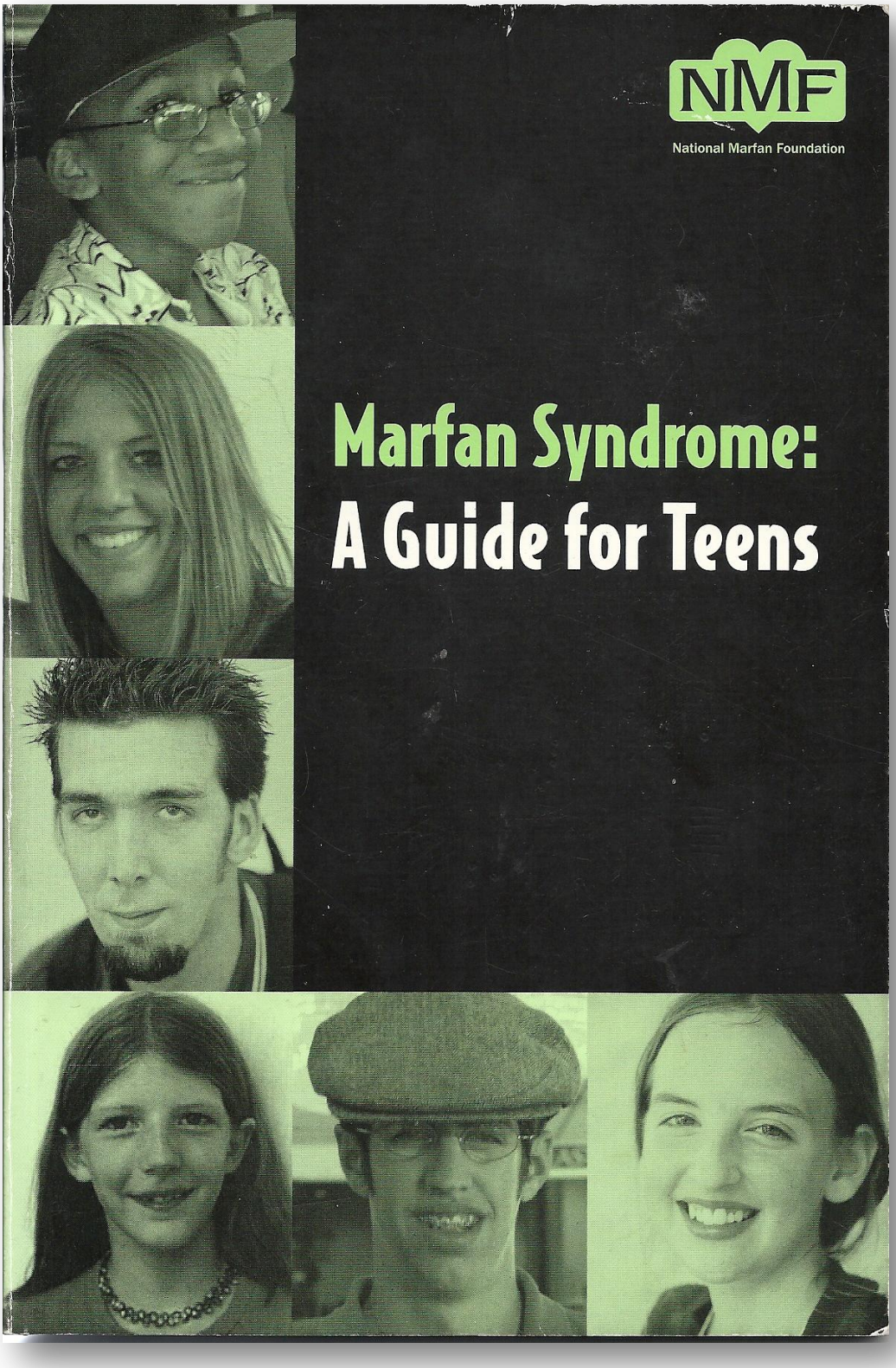
ad § 6.9 | Bibliography

[141] This LTP has to be solved with transposition: the compound noun ‘Cardiac Articles’ in the ST must become the noun phrase ‘Artikelen over Hartafwijkingen’ in the TT.

[142] The Bibliography is needed for legal reasons, so it must be copied exactly into the TT. That gives rise to the application of visibility change.

[Appendix 2]

Examples of Original Source Text



HAVING MARFAN SYNDROME CAN BE *a scary thing, whether you are newly diagnosed or have known about it for years. There are probably hundreds of thoughts, questions and concerns rushing through your head. That is normal. This booklet is designed to give you some of the answers you need.*

The booklet also serves as your first introduction to a special community. It is much easier to deal with questions and concerns when you are surrounded by supportive and caring people. A community, at its best, pushes you to achieve anything you dream of. You now have the opportunity to be a part of a community that can do just that.

You may also be feeling some very powerful emotions. As you will see from the comments from other teens in this booklet, these emotions are not uncommon. Many people in our community have come to realize that Marfan syndrome is a part of who they are. It is no more a part of them than anything else. That realization has helped many to live full lives despite any challenges that may arise.

In addition, this booklet will help connect you to some very valuable resources. There are so many different kinds of people who would love to talk to you. No matter what you may be facing, there are people who can give you information. Everyone, from doctors to your peers, is at your fingertips. Inside you will find information on how to connect to people in the Marfan community.

It is important to take the time to learn what you can. Ask what you need to ask, and talk to whom you need to talk. I hope this booklet is a helpful step in your Marfan education.

Ben Weisman

Ben Weisman, age 22
NMF Conference Teen Group Leader

TEEN PERSPECTIVE:
"My condition has had a profound influence on my family. Because of it, my brother and I are very close and depend on each other a lot more than stereotypical siblings. He is very athletic and pushes himself to do better on and off the field, partially because he knows he's doing it for both of us. He tells me that I'm his role model, that my persistence and positive attitude help him strive to do better and to remember what is really important in life. My relationship with my parents is also a lot closer, in part because of my condition and in part because they are actually cool people. This might not be what you might expect to hear from a teenager, but I think that my condition has lead us to an unwritten, unsigned pact of teamwork where we all depend on each other."

–Micah

V. Living with Marfan Syndrome

Family Issues

Having Marfan syndrome affects not only the person with the disorder, but also the whole family. Each family member reacts differently to the news of a diagnosis and the ongoing issues. This is true in families with several affected people and when there is only one person with Marfan syndrome. Here are some emotional issues that often arise in families:

- Many children feel angry at the parent from whom they inherited Marfan syndrome. Or, if a person has a spontaneous mutation, some may feel angry that the parents might have done something to cause the mutation.
- An affected child may feel jealous of any brothers or sisters who do not have Marfan syndrome.
- Unaffected children may feel jealous of the sibling with Marfan syndrome because that person gets extra attention.
- An affected child may be upset by parents who share medical information with other family and friends without first asking the child if that is o.k.
- A child may be angry if parents are overprotective or if they provide constant reminders about taking medications or limiting physical activity.
- Parents may feel that they want to protect children from in-depth understanding of their condition.
- Parents may become very upset about the

HELPFUL HINT:

Taking your medications on schedule and keeping your physical activity within prescribed limits will show your parents that you are responsible and provide evidence they do not need to constantly remind you how to care for yourself.

TEEN PERSPECTIVE:

"Marfan syndrome brings with it the entire gambit of emotions from tranquility to pain to anger to depression and back again. Marfan syndrome can cause any emotion at any time. Having a support team of family and friends is vital for those times when personal perspective is not enough."

– Matt

21