Patient Association
CMTC-OVM
www.cmtc.nl

Annual Report 2013

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Approval

Name	Role
J. Schipper	Treasurer
A. Eveleens	Secretary

Distribution

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Not applicable.

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1 Introduction

1.1 Document Purpose

This document is the 2013 Annual Report for the patient organisation CMTC-OVM Association, formerly the Association for people with Van Lohuizen Syndrome. The primary purpose of this document is to provide an overview of the activities carried out in 2013.

1.2 Introduction

The CMTC-OVM Association was formally established on January 22, 1997 by notary Van Helden in Amsterdam and then registered at the Chamber of Commerce in Amersfoort. The purpose of the Association, which is laid down in the statutes, is expressed in the text below.

The Association mission is as follows:
Promoting the well-being of people who suffer from vascular malformations such as CMTC (“Van Lohuizen syndrome”), in particular its own members and the promotion and development of activities that promote this welfare. Promoting scientific research on vascular malformations such as CMTC, the causes and treatment thereof, and all that in the broadest sense of the word.

The name is: CMTC-OVM which stands for Cutis Marmorata Telangiectatica Congenita and Other Vascular Malformations.

The Association logo is as follows:

1.3 Board

The Board is comprised of the following members as of December 31st 2013:

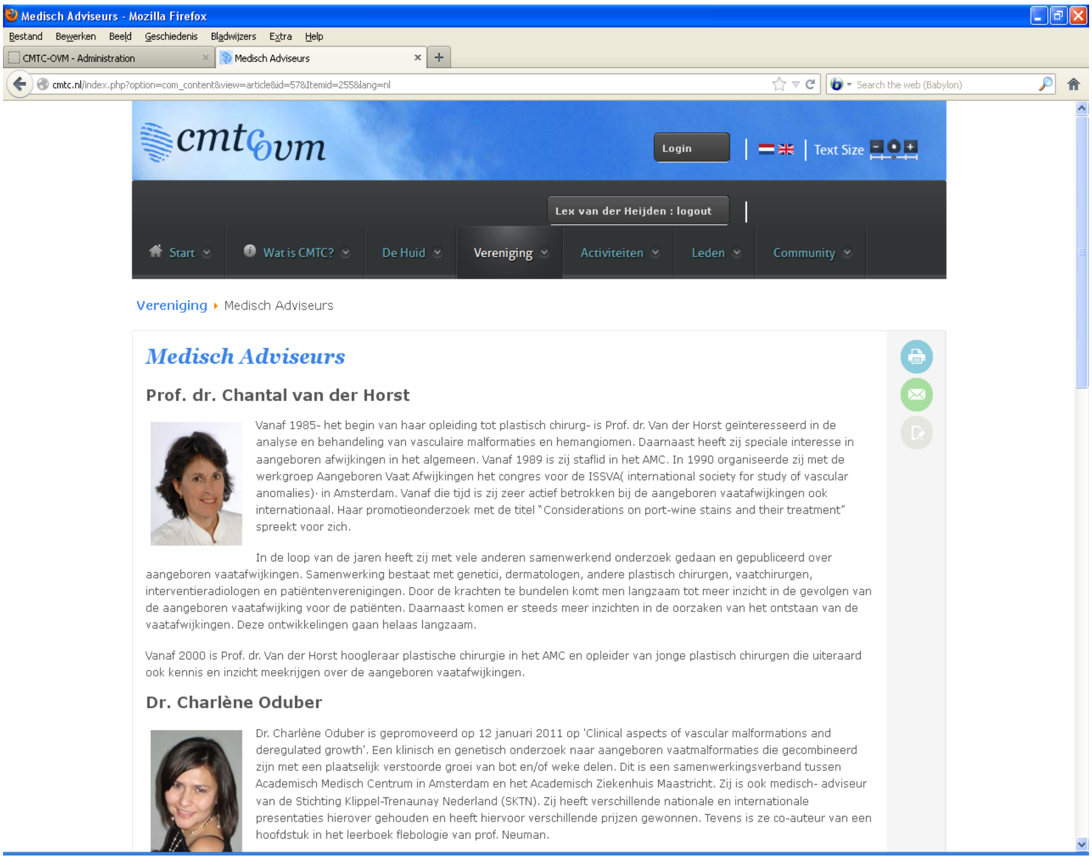
Dhr. A.F.R. van der Heijden	Chairman
Vacant	Secretary
Dhr. A. Fidder	Treasurer

1.4 Medical Advisors

Our current specialist medical advisors are: Prof. Dr. C.M.A.M. van der Horst, Prof. Dr. A.P. Oranje, Prof. Dr. S. Pasmans, Prof. Dr. M. van Steensel, Dr. W.W. van der Schaar, Drs. Siderius and Dr. C. Odubèr.

We also work closely with other doctors from several countries including Dr. Millan Patel in Canada for example, in the context of our genetic research activities.

Our website provides further details concerning the medical advisors.



Medisch Adviseurs

Prof. dr. Chantal van der Horst

Vanaf 1985- het begin van haar opleiding tot plastisch chirurg- is Prof. dr. Van der Horst geïnteresseerd in de analyse en behandeling van vasculaire malformaties en hemangiomen. Daarnaast heeft zij speciale interesse in aangeboren afwijkingen in het algemeen. Vanaf 1989 is zij staflid in het AMC. In 1990 organiseerde zij met de werkgroep Aangeboren Vaat Afwijkingen het congres voor de ISSVA(international society for study of vascular anomalies)· in Amsterdam. Vanaf die tijd is zij zeer actief betrokken bij de aangeboren vaatafwijkingen ook internationaal. Haar promotieonderzoek met de titel "Considerations on port-wine stains and their treatment" spreekt voor zich.

In de loop van de jaren heeft zij met vele anderen samenwerkend onderzoek gedaan en gepubliceerd over aangeboren vaatafwijkingen. Samenwerking bestaat met genetici, dermatologen, andere plastisch chirurgen, vaatchirurgen, interventieradiologen en patiëntenverenigingen. Door de krachten te bundelen komt men langzaam tot meer inzicht in de gevolgen van de aangeboren vaatafwijking voor de patiënten. Daarnaast komen er steeds meer inzichten in de oorzaken van het ontstaan van de vaatafwijkingen. Deze ontwikkelingen gaan helaas langzaam.

Vanaf 2000 is Prof. dr. Van der Horst hoogleraar plastische chirurgie in het AMC en opleider van jonge plastisch chirurgen die uiteraard ook kennis en inzicht meekrijgen over de aangeboren vaatafwijkingen.

Dr. Charlène Oduber

Dr. Charlène Oduber is gepromoveerd op 12 januari 2011 op 'Clinical aspects of vascular malformations and deregulated growth'. Een klinisch en genetisch onderzoek naar aangeboren vaatmalformaties die gecombineerd zijn met een plaatselijk verstoorde groei van bot en/of weke delen. Dit is een samenwerkingsverband tussen Academisch Medisch Centrum in Amsterdam en het Academisch Ziekenhuis Maastricht. Zij is ook medisch- adviseur van de Stichting Klippel-Trenaunay Nederland (SKTN). Zij heeft verschillende nationale en internationale presentaties hierover gehouden en heeft hiervoor verschillende prijzen gewonnen. Tevens is ze co-auteur van een hoofdstuk in het leerboek flebologie van prof. Neuman.

1.5 Volunteers

The Association is exclusively staffed by volunteers, including the Board. In addition to membership of the Board, volunteers are actively engaged in a number of activities such as translation work for example. In addition to the Board, as of December 31st 2013, 15 volunteers are active especially in the area of translation support and also providing assistance during meetings

1.6 Announcements

In 2013 sadly one of our volunteers, Ria Maas, passed away. Ria was actively involved as a helper during our meetings in The Netherlands for many years and was always able to provide a reception to our guests in a very warm and generous manner. Those who knew her were shocked to hear of this news at the meeting on 2nd November.

2 Activities 2013

2.1 Introduction

With the help of a grant from FondsPGO in particular, we were able to carry out a large number of additional activities in 2013.

The main activities carried out in 2013 were:

1. Organizing a Family Day for patients and immediate family in The Netherlands.
2. Organizing a General Meeting in The Netherlands and USA.
3. Founding CMTC-OVM US.
4. Offering free medical examinations.
5. Actively propagating our Association by means of marketing.
6. Participate in conferences.
7. Rebuilding and expanding the website.
8. Genetic research in Canada.
9. Other activities.

2.2 Family Day

In 2013 for the fifth time, we organized a Family Day for patients and their immediate family. This was once more a great success and about 60 people joined us for the day at the Efteling theme park.

The responses and feedback were very positive and the members had plenty of time to get to know each other and to share experiences.

Videos taken on the day can be found on the website together with photographs from the event and a report from one of your young members.

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2.3 Meetings

In 2013 we organised two General Meetings. In July in St. Louis USA, Prof. Dr. van Steensel also attended and we were able to offer the opportunity of a free diagnosis (more than 10 people made use of this offer) and the most diverse medical questions could be asked. Members present made grateful use of this opportunity. The number of participants was around 55 this year. The day before the meeting a Family Day was arranged at the St. Louis zoo.

The Netherlands General Meeting was held in November. Members from Australia & Switzerland, Germany, Japan & Dubai, The Netherlands and the USA were present. The number attending was around 70 people. Our members could obtain a free medical diagnosis and full use was made of this facility. Three medical professors and a medical psychologist were available with a considerable breadth of knowledge and experience.

This year again participants could choose from a series of parallel sessions, in total 6 sessions, with various subjects as a key theme. The psychologically oriented parallel sessions were especially well attended.

Meeting reports with photos are available via our website.

2.4 CMTC-OVM US

The USA CMTC-OVM chapter successfully held their first independent General Meeting in 2013. The big challenge now is to become financially independent from the worldwide organisation in The Netherlands. This year Prof. Dr. Maurice van Steensel has again visited to carry out a medical diagnosis for around 10 patients. The diagnosis can regularly be a somewhat disturbing surprise for the parents of these often young patients. We also then have someone available to provide psychological support for the parents.

2.5 Medical Examination and Diagnosis

Thanks to the collaboration of Prof. Dr. van Steensel we are able to offer our members free medical examination and diagnosis in the academic hospital Maastricht. Up to this moment, 40 members from various countries (such as Aruba, Australia, Canada, Croatia, Denmark, England, Italy, Greece, Hong Kong, Norway, USA and Sweden) have made use of this opportunity.

2.6 Marketing

How we increase our brand awareness and how we thereby assist more patients was our question for quite some time. We have developed a marketing plan which enables us to increase our visibility using modern internet technology.
We measure the effects of actions by means of website statistics so that we can determine the extent to which the action for us has had sufficient results.
In 2012 we had created unique CMTC-OVM pens with the new logo and these are still in stock.

2.7 Conferences

Participating in conferences has a number of important goals especially for organizations which are active in the field of rare diseases. Cooperation is the key word in this context. Networks, brand awareness and learning from each other are also important keywords.
We visit particular international conferences of large organizations in order to make and maintain important contacts via networking.

The experience has been that the time between planting and harvesting is measured in years and that you have to keep seeding.

In 2013 we have participated in the following international conferences:

1. Eurordis in Croatia.

2. NORD/DIA in the USA. Not only the global Netherlands Organization was represented but also the American CMTC-OVM organization.

For a report of the different conferences we refer you to our website.

2.8 Website

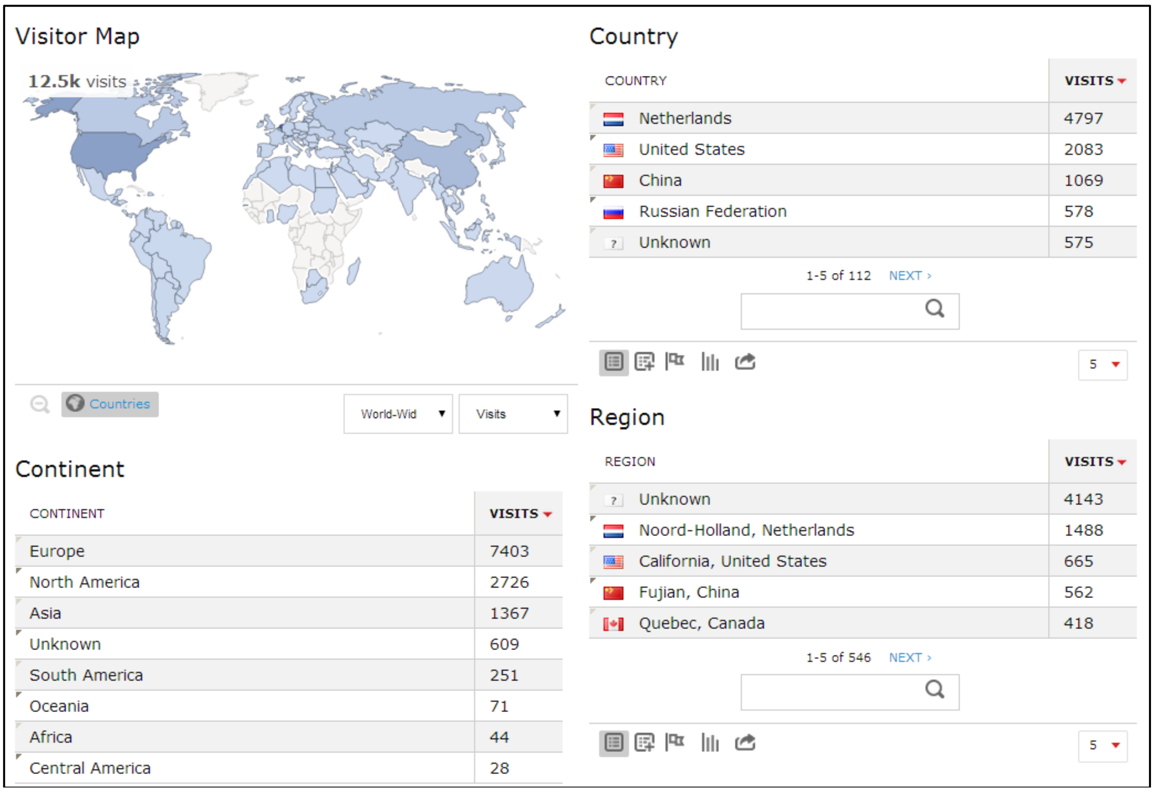
Our website is our main medium to share information.

For example, reports from practically all conferences which we have attended can be found there. Separate pages are created for donors, volunteers and sponsors. Also the homepage has been changed in the course of the year and the use of social media is integrated into our website

The security of the website has been further expanded to protect the privacy of our members. We are paying a lot of attention to security partly because we saw that in 2012 approximately 7000 attempts per month were made to break into our website. We want to prevent personal information of members, donors etc. from getting into the hands of people with wrong intentions.

The statistics which we use in order to determine the effect of certain actions, among other things, is an important tool in our marketing. Below an example of our statistics.

We use these statistics to determine which search keys are used to find our Web site and to determine the effect of certain activities.



Visitor Map

Continent

CONTINENT	VISITS
Europe	7403
North America	2726
Asia	1367
Unknown	609
South America	251
Oceania	71
Africa	44
Central America	28

Country

COUNTRY	VISITS
Netherlands	4797
United States	2083
China	1069
Russian Federation	578
Unknown	575

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Region

REGION	VISITS
Unknown	4143
Noord-Holland, Netherlands	1488
California, United States	665
Fujian, China	562
Quebec, Canada	418

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Mark Knopfler, Dire Straits, has given approval to use his music for the videos that have been made, composed of single pictures.

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2.9 Genetic Research

Thanks to many years of international networking we managed to start a genetic research program into the causes of CMTC.

This research is being conducted in Canada in collaboration with some of our medical advisors. Dr. Millan Patel on the picture leads this genetic research program in Canada.

This research is free of charge for our organization which would not have been possible if we needed to fund this program ourselves. The costs of such a program are between € 35,000 and € 50,000.

In 2012, a number of patients that met certain criteria, had given biopsies (a piece of skin tissue), which will be examined in Canada. Unfortunately the research was not able to start as planned in 2013 because the transfer of human tissue to Canada requires a significant administrative overhead, due in the main part to legal requirements.

2.10 Overview of Other Activities

Here follows an overview of various other activities during 2013:

1. For all of the roles in our organisation we have made a profile description. These are publically available on our website.

2. We have extended our website with a separate psychological section and a separate information folder in this area.

3. The website has also been extended with a number of extra subject items on skin. These subjects are: skin ageing, melanomas and birthmarks and finally skin therapy.

4. We have developed a ‘social media’ plan for implementation in 2014.

5. We have held our first ‘bottle return deposit’ action at a supermarket and this gave us the sum total of €180. We intend to involve more members with a similar activity in 2014. A positive side effect from this kind of event is that the name recognition of our organisation is increased further.

6. The Filmproject Society produced a number of short documentaries with the aim of providing information on and raising awareness of people with CMTC and other vascular malformations. In the films the various psychological aspects of the condition that impact the patients and their parents are covered. There are costs involved for production of this material. The delivery of the final edited films will be made in 2014. The films will be distributed via YouTube and our website.

7. We have taken the initiative to meet together with other patient organisations with the aim of discovering how we can help and assist each other, learn from each other and what we could organise together. These other organisations were: Hevas, Klippel-Trenaunay and Sturge-Weber. We had approached these organisations as they are active in the same area in terms of conditions for vascular malformations. The initiative has now been stopped for some of these due to significant differences on the direction to be taken. We will continue to work together with the Sturge-Weber organisation.

8. We have developed a donor’s folder which can be downloaded from our website in ‘PDF’ format.

9. On the 2nd March 2013 on of our medical advisors Prof. Dr. Maurice van Steensel received the Angel Award. He had received this Dutch national award under the worldwide Rare Diseases Day in The Netherlands. We had proposed him for this award for his enormous personal contribution over many years and are very proud of him for being recognised with this award.

3 Financial Information

3.1 Introduction

The year 2013 was not a good financial year for us although we could perform activities in various areas and could further strengthen our position.

Below an overview of the different main items for expenditure and income.

The main items largely correspond to the structure which the Dutch Government organization FondsPGO uses, namely:

1. Contacts.
2. Information.
3. Advocacy.
4. Capacity-enhancing activities.

3.2 Expenditure

Activity	Expenditure 2013 (€)	Expenditure 2012 (€)
Contacts	22.522	22.845
Information	14.600	16.694
Advocacy	6.215	6.553
Capacity-enhancing activities	6.958	4.465
Total	**50.295**	**50.557**

3.3 Income

Source	Income 2013 (€)	Income 2012 (€)
FondsPGO Grant	35.000	34.850
Membership Fee	1.845	1.825
Donation/gift/miscellaneous	7.974	11.362
Total	**44.819**	**48.037**

3.4 Notes

The main items in the category ‘Contacts' are formed by two members’ meetings in The Netherlands and the United States.
We have made an additional contribution to patient medical research at University Hospital Maastricht in the general interest of other patients.
During the Assembly of members in Netherlands there is also in a separate hall with children's entertainment organized so that parents can attend the meeting and the children will be kept busy in all kinds of ways, taking into account the age of the children.
The financial position of the USA based organisation was ultimately insufficient to bear a significant portion of their costs with the result that The Netherlands organisation provided financial support.
We have also acquired new hardware equipment such as a beamer for the General Meeting.

Finally, the Chairman of The Netherlands Board and the Chairman of the USA Board attended the annual NORD meeting together in the USA.

In 2013 we organized a Family Day with the aim of bringing together not only patients but also their immediate family in a single environment and to have fun together, get to know each other and to share experiences.

	2013	**2012**
Utilisation Rate Expenditure (%)	86.17	91.17
Utilisation Rate Income (%)	96.69	95.11

4 Look Ahead

Experience shows that it takes many years for a patient organization to gain visibility. For rare condition organizations this is even harder which requires a lot of effort, also in financial areas.

All kinds of address guides are updated once a year so that it takes at least a year before a new organization is to be found in such guides. Given the rarity of the condition, we expect slow growth over the next few years.

International contacts will also continue to increase as well as the number of foreign members. Through Internet technology, we want to strengthen our network worldwide and act as a focal point between doctors and patients.

Contacts via NORD, Eurordis, and Genetic Alliance are expected to become more and more important for a small organization like ours because it would not be possible to achieve this on our own. Working together and sharing knowledge and experience is also crucial with the ultimate aim of improving the lives of patients.

In the year 2014, we want to include the following activities:

1. Maintain and expand our contacts and work with both patients and other patients' associations, both at home and abroad.

2. Maintain and expand our contacts with medical specialists like dermatologists, both at home and abroad.

3. Research vascular malformations such as CMTC. We are thinking in particular of DNA genetic research material of patients.

4. Implementation of ‘social media’. For example including the use of FaceBook and Twitter.

5. Fundraising in order to be able to develop extra activities and become less reliant on funding subsidy from the Dutch Government.

6. Organizing a meeting for personal contacts and exchange of information in the form of a meeting in both the Netherlands and USA

7. Organizing a family day in the Netherlands in a casual setting where the attention is focused on working together with patients and their immediate family. This also provides the opportunity to gain knowledge and exchange experiences.

8. Building and expanding the website including:
    a. Other vascular malformation information.
    b. Special part for children (child language use, etc.).
    c. The website for the use of different modes of access. The tipping point will be reached as more users view websites with smartphones and tablets than with normal computers. The presentation for these smaller monitors should be different than for large displays.

    For these different extensions we define projects which will be funded separately.

9. Attending national and international conferences in the field of rare diseases. We are thinking here in particular about conferences such as Eurordis and NORD.

10. Recruiting members and donors and obtaining grants to increase the visibility of the association with as main goals to be able to support more people and to gather information on the condition.

11. Patient information folders for Other Vascular Malformations designed and published in different languages. Currently the CMTC folder is available in 6 languages (Dutch, German, English, French, Russian and Spanish). Other languages may be added during the year.

12. Further development of our website such as integration of member administration and financial administration and all sorts of other articles.

13. Maintaining the security of the dangers which come from the Internet. The main dangers are viruses and intrusion into the computers used by the board members and illegal access to our website.

14. Continued professionalization such as development and implementation of a fundraising strategy, profile descriptions for Board members and other volunteers, registration of action points from meetings in a software tool, integration with the website for a procedure handbook and improved website navigation.

5 Staff and Resource Availability

The number of available people is quite limited in a small association. The amount of work, however, is not proportional to the size of an association which means that there is still a considerable quantity of work to be done. The Board consisted during most of the year 2013 of four people although the Secretary and another general Board Member left in November 2013. The new Board consists of three people.

Through the use of additional volunteers for translation work and various other activities a lot of work is done. We intend to involve more members in activities such as the recruitment of members and donors, fundraising activities, attending conferences and such like.

Thanks to the new subsidy structure we do now have a significant subsidy fund available that allows us in the first instance to improve the quality of life for CMTC patients and their close family. In addition these funds will allow us to continue to develop the organisation in a professional manner.

In 2014 a new volunteer will be dedicated to the use of ‘social medial’. This is a relatively economical way to raise our profile and to be able to reach out to and to help more individuals.

6 CMTC-OVM and Environment

Just like a commercial organisation our activities can have also have a negative environmental impact. We have taken the following measures to limit any adverse environmental impact:

1. Newsletters are generally made available via the website and only exceptionally printed on paper and sent by post.
2. Printing on paper is done where possible double-sided.
3. Travel by car when necessary is shared with other persons.
4. Computers are only switched on when they are actually used.
5. Conferencing by telephone if possible, for example via Skype.
6. The medium e-mail is preferred over physical post.
7. Empty inkjet cartridges are collected and submitted at drop-off points. We receive €1 discount per cartridge when buying new Hewlett Packard cartridges.
8. Paper, plastic and chemical waste are separated from other waste.
9. Material is reused as much as possible.

A. Appendix – Terms en Abbreviations

Term/afkorting	Verklaring
ANBI	Formal status of a non-profit organisation from the Dutch Tax Authority which implies that donations are tax deductible.
CMTC-OVM	Our organization.
Eurordis	European Organisation for Rare Diseases.
FondsPGO	Arranges subsidy from the Dutch Government for national disabled people and patient organisations.
NORD	National Organization for Rare Disorders (USA).
VSOP	The Dutch Genetic Alliance, an umbrella organisation of about sixty national, disease-linked, parent and patient organisations (NL).