

POLICYPLAN 2017-2019 - MSS RESEARCH FOUNDATION

MSS Research Foundation contributes worldwide to the happiness of children with MSS and their families by handing solutions to make daily life with MSS liveable and by helping families to become stronger.

GOALS

Solutions for a liveable daily life with MSS

- There are interactive and updated standards of care and a patientedition.
- Centre of expertise is working international
- 80% of the families worldwide have access to the foundations' knowledge and information about MSS
- There's a list of promising research options.

Making families stronger

- Digital meetings and sharing lives between families
- Live meetings and sharing between families

Financial resources

- Fundraising in 5 countries
- Another 50 friends of MSS in NL (growing from 120 to 170), 100 international friends (from 0 to 100)
- External funds support the MSS Foundation

Worldwide

- There are MSS ambassadors in 10 countries spread over different continents
- The MSS foundation operates on a new continent: Asia, Australia or Africa



STRATEGIES

- Families worldwide are reached by international approach
- Basic information about MSS on the MSS website's landing page in 15 largest languages and in all languages of known MSS-families

- Enable MSS research by international fundraising
- Fundraising for translations by external funds.

- Facilitating digital meetings through platforms and other applications to learn together and to support each other
- Enable live meetings between families

- Finding new solutions for living with MSS by gathering information from families and hand this to researchers
- The MSS foundation has a network with the best researchers with heart for MSS

- Use new technologies to support families in daily life with knowledge and information
- Interactive information about living with MSS from current and new sources

DASHBOARD

- Worldwide +10 ambassadors in +10 different countries
- Basic languages EN, FR, SP en POR
- Landing page in +15 languages and on +4 new social media en search engines

- > 1.000.000 euro cumulative income on 31-12-2019
- 20k /year international gifts and 50k /year from NL for research
- +50 friends NL +100 international
- 1 international fundraising campaign
- Donations from 5 different countries
- Research funding for at least 2 years

- 80% of the parents join community
- 50% of the parents have an active role in the community
- MSS Family Event in 2017 en 2019, with about 15 families, 4 new families
- Advice internat. expertisecentre

- >100.000 euro/year for promising research (together with funds)
- 3 scientific publications
- Review article about MSS in top journal
- Updated standards of care and patient version by 2019

- +40 ouders use Waihonapedia
- 75% of our resources is interactive
- 75% of the parents know and use the MSS expertisecentre's website

ACTIONPLAN (what, when)

- Landing pages in 15 languages and for all languages of the families we know (2017)
- Use Search engines and social media worldwide to make our landing pages findable (2017)
- Develop ambassador concept and recruit 10 of them (2017)
- Contact clinical geneticists worldwide through Prof. Dr. Hennekam's network (2017-2019)
- Landing page MSS in new languages (e.g. Chinese) (2018)
- Actionplan for follow-up contact after the landing page (2018)

- Develop and implement concept MSS-friend (2017)
- Recruiting MSS friends by families (2017-2018)
- Research in how to do succesful fundraising in other countries and cultures (2017)
- Create projectplan and finding funds for translations (2017)
- Create fundraising plan and implementing it (2018)
- Start international fundraising (2018-2019)

- Organize MSS Family Event (2017 and 2019)
- Investigate the families' expectations about community (2017)
- Live meeting (potential) ambassadors worldwide (2018)
- Investigate suitable options for online meeting places(2018)

- Researchers meeting during MSS Family event (2017 en 2019)
- Updated research agenda (2017-2019)
- Ask Prof. Dr. Hennekam to take charge of an updated MSS review article MSS (2017-2018)
- In response to review article: inventing new solutions to problems of living with MSS (2019)
- Update standards of care by workgroup (2018)
- Finding external funds for (extra) contribution to research (2018)

- Examine foundation's role in internationalizing the expertisecentre (2017)
- The expertisecentre's website is multiple language (2017)
- Webinar during MSS family event (2017 en 2019)
- Stimulate use of Waihonapedia and learn how to use it (2017-2018)
- Examine if current information is accessible enough and make a plan how to improve this (2017)
- Online consultation / office hour with MSS experts (2018)

Stronger family ties, more scientific research, focus on all continents

On Joas' birth in 2006, his parents were informed by the doctors: "Allow for a life expectancy of three years". Joas has the Marshall-Smith syndrome. As a result of this very rare disease he is both physically and mentally handicapped. Meanwhile it is now eleven years later and despite his limitations Joas enjoys life. The longer life expectancy is partly due to the MSS Research Foundation, which devotes itself worldwide to these children and their parents. The policy of the foundation in the next years to come is aimed at three specific targets.



Otto Mak

Focus on all continents

It is MSS foundation's intention to strengthen its international character.

"We are going to make all our information and tools also available in other languages" says director Otto Mak. "Besides we want to locate families, who have a child with the Marshall-Smith syndrome, on more continents. At present our knowledge of their whereabouts is restricted to Europe and America, but we do not know how many of them live in Asia and Africa. We want to offer them information in their language too and to guide them into contact with fellow-patients. The more families we know the better support we can provide."

More scientific research

More money for scientific research into MSS is another target. "Not because we think we can cure MSS but to solve specific problems", says Mak. He mentions the accelerated ageing of the bones from puberty age onwards. The result is a warped back, organs are being squeezed, which is one of the reasons that many MSS patients do not grow old. "Research into this has started in Oxford. It could lead to further research. To enable this we want to raise money continuously, because the government does not finance research for such a small target group. Everything will have to be carried out using private funds.

Stronger family ties

The MSS foundation is going to intensify the contacts between fellow-patients. This is already happening during the bi-annual international family weekends, but nowadays digital meetings are also an option. Mak: "These families live far apart and travel with a child, suffering from MSS, is very complicated. Which is why we are going to use more modern techniques like social media and digital platforms. In a life with MSS nothing is self-evident. Parents are badly in need of exchanging knowledge and concrete information and to encourage each other. Their understanding of each other cannot be matched by anyone else."

Help to make life tolerable

When Joas' parents invited their friend Otto Mak to become director of the MSS foundation he did not need long to decide. "I had observed the extreme difficulties of having a child with a rare disease. It requires a lot of energy to organize everything, both in the medical circuit and in the daily life. Your child has to be supported in everything, every day and life-long. I gladly offer my support to make life more endurable for these families."

Marshall-Smith Syndrome Research Foundation

- In the Netherlands three children are known to have the MSS syndrome, worldwide there are fifty of these children.
- The MSS Research Foundation was established in 2007.
- Become a Friend of the MSS Foundation. Go to www.marshallsmith.org

