

Policy Plan 2020-2023	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	STRATEGIES	DASHBOARD	ACTION PLAN (what, when)
<p><b>Solutions for a liveable daily life with MSS</b></p> <ul style="list-style-type: none"> <li>➤ There are interactive and updated standards of care and a patient edition</li> <li>➤ Center of expertise is working international</li> <li>➤ 80% of the families worldwide have access to the foundations' knowledge and information about MSS</li> <li>➤ There's a list of promising research options</li> </ul> <p><b>Making families stronger</b></p> <ul style="list-style-type: none"> <li>➤ Digital meetings and sharing lives between families</li> <li>➤ Live meetings and sharing between families</li> </ul> <p><b>Financial resources</b></p> <ul style="list-style-type: none"> <li>➤ Fundraising in 10 countries</li> <li>➤ Another 100 friends of MSS in NL (growing from 100 to 200), 100 international friends (from 0 to 100)</li> <li>➤ External funds support the MSS Foundation</li> </ul> <p><b>Worldwide</b></p> <ul style="list-style-type: none"> <li>➤ There are MSS ambassadors in 10</li> </ul>	<ul style="list-style-type: none"> <li>➤ Families worldwide are reached by international approach</li> <li>➤ Basic information about MSS on the MSS website's landing page in the 10 most widely spoken languages and all languages of the MSS-families we know</li> </ul>	<ul style="list-style-type: none"> <li>➤ Worldwide +10 ambassadors in +10 different countries</li> <li>➤ Basic languages EN, FR, SP en POR</li> <li>➤ Landing page in +10 languages and on +4 social media and search engines</li> </ul>	<ul style="list-style-type: none"> <li>➤ Landing pages in the 10 most widely spoken languages and for all languages of the MSS-families we know (2020)</li> <li>➤ Use search engines and social media worldwide to make our landing pages findable (2021)</li> <li>➤ Develop ambassador concept and recruit &amp; support 10 of them (2021)</li> <li>➤ Contact clinical geneticists worldwide through Prof. Dr. Hennekam's network (2020-2022)</li> </ul>
	<ul style="list-style-type: none"> <li>➤ Enable MSS research by international fundraising</li> <li>➤ Fundraising for translations through external funds</li> </ul>	<ul style="list-style-type: none"> <li>➤ 100.000 euro/year for research, together with Malan Foundation; 25.000 – 50.000 of this is from MSS Foundation</li> <li>➤ At least 20k/year international gifts and 50k/year from NL for research</li> <li>➤ +100 friends NL, +100 international</li> <li>➤ 1 yearly international fundraising campaign</li> <li>➤ Donations from 5 different countries</li> <li>➤ Research funding for at least 2 years ahead</li> </ul>	<ul style="list-style-type: none"> <li>➤ Develop and implement concept MSS-friend (2020)</li> <li>➤ Recruit MSS friends by families NL (2020-2022)</li> <li>➤ Recruit MSS friends international: develop plan with international families during Family Weekend (2021)</li> <li>➤ Align wish for translations with international families (2020-2021)</li> <li>➤ Create and implement fundraising plan (2020-2021)</li> <li>➤ Set up (international) activities for fundraising on a regular basis from the JoinMSS fundraising platform (2020-2022)</li> <li>➤ Connect to board of Malan Foundation and create joint fundraising</li> <li>➤ Annual international fundraising day on September 5th (2020-2022)</li> </ul>
	<ul style="list-style-type: none"> <li>➤ Facilitating digital meetings through platforms and other applications to learn together and to support each other</li> <li>➤ Enable live meetings between families</li> </ul>	<ul style="list-style-type: none"> <li>➤ 80% of the parents join the community</li> <li>➤ 50% of the parents have an active role in the community</li> <li>➤ MSS Family Events in 2021 en 2023, with about 10 families, 2 new families</li> <li>➤ Advice internat. Centre of Expertise</li> <li>➤ Webinars 2x/year</li> </ul>	<ul style="list-style-type: none"> <li>➤ Organize MSS Family Event (2021 en 2023)</li> <li>➤ Organize webinars with a theme (2020-2022)</li> <li>➤ Apply possibilities WaihonaPedia due to Frequently Asked Questions and important themes (2020-2022)</li> <li>➤ Update standards of care by workgroup and parents by using Waihonapedia</li> </ul>
	<ul style="list-style-type: none"> <li>➤ Finding new solutions for living with MSS by gathering information from families and hand this to researchers</li> <li>➤ The MSS Foundation has a network with the best researchers with heart for MSS</li> </ul>	<ul style="list-style-type: none"> <li>➤ &gt;100.000 euro/year for promising research (together with funds)</li> <li>➤ 3 scientific publications</li> <li>➤ Review article about MSS in top journal</li> <li>➤ Updated standards of care and patient version by 2021</li> </ul>	<ul style="list-style-type: none"> <li>➤ Researchers meeting during MSS Family event (2021 en 2023)</li> <li>➤ Ask families about their research needs (2020)</li> <li>➤ Updated research agenda (2020-2022)</li> <li>➤ Explore possibilities of joint research agenda with Malan Foundation (2020-2021)</li> <li>➤ Ask Prof. Dr. Hennekam to take charge of an updated MSS review article (2021)</li> </ul>

<p>countries spread over different continents</p> <p>➤ The MSS foundation operates on a new continent: Asia, Australia or Africa</p>			<ul style="list-style-type: none"> <li>➤ In response to review article: inventing new solutions to problems of living with MSS (2021-2022)</li> <li>➤ Update standards of care by workgroup (2021)</li> <li>➤ Finding external funds for (extra) contribution to research (2021)</li> </ul>
	<ul style="list-style-type: none"> <li>➤ Use new technologies to support families in daily life with knowledge and information</li> <li>➤ Interactive information about living with MSS from current and new sources</li> </ul>	<ul style="list-style-type: none"> <li>➤ +25 ouders use Waihonapedia</li> <li>➤ Center of expertise is available for all families worldwide</li> <li>➤ 75% of the parents knows/uses their access to Center of Expertise</li> </ul>	<ul style="list-style-type: none"> <li>➤ Consult with Center of expertise regarding internationalization of the Center (2020-2021)</li> <li>➤ Website Center of expertise in multiple languages (2021)</li> <li>➤ Webinar during MSS family event (2021)</li> <li>➤ Use WaihonaPedia's possibilities and encourage the use of it among families (2020-2022)</li> </ul>