



Sirius e.V.

VEREIN FÜR SELBSTHILFE, INFORMATION UND RAT
IM UMGANG MIT DEM SMITH-MAGENIS-SYNDROM

www.smith-magenis.de



Link to flyer in Englisch:

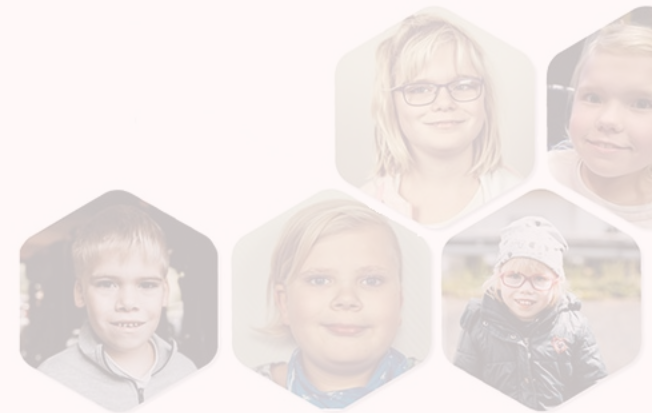
https://smith-magenis.de/wp-content/uploads/2022/07/Flyer_eng.pdf





History

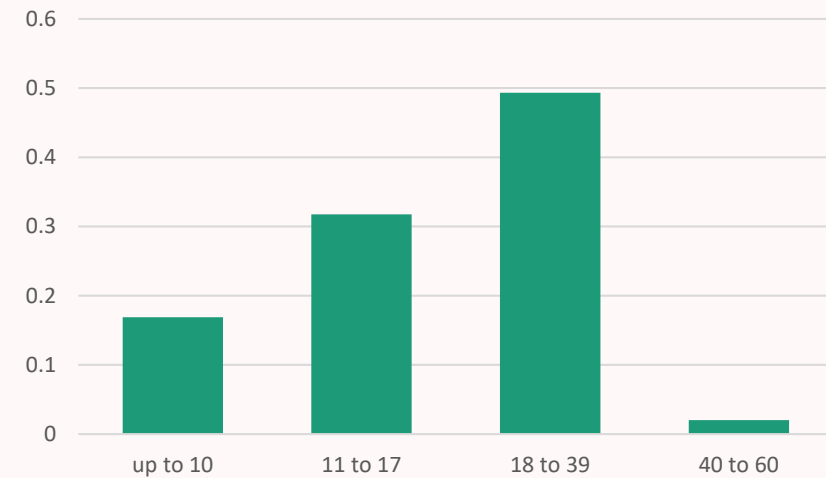
- 2001: LEONA e.V. (charity for families with rare chromosomal variations) helped connect SMS families.
- 2003: Armin Mutscheller founded Sirius with 5 families from Germany and Austria.
- Sirius e.V. is a registered charity in Germany



Members

- 156 SMS people and their families.
- Some live in Switzerland, Austria, Montenegro, Slovakia, UK
- Most new members younger than 10 years.

Age distribution Sirius members





Trustees/Senior Team



President

Klaus Rößler



Vice President

Quint Seijkens



Finance

Berta Rößler



Secretary

Marie-José
Rosenwald



Honorary President

Armin Mutscheller

Associates

Public Relations

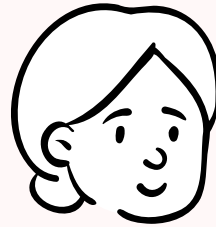


Jana Vogt



Anne
Ottenbacher

Organisation



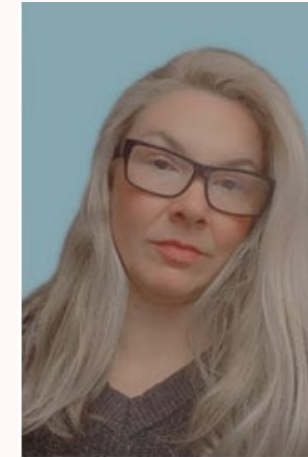
Anja Reißig &
Ingrid Groß

Advisory Board

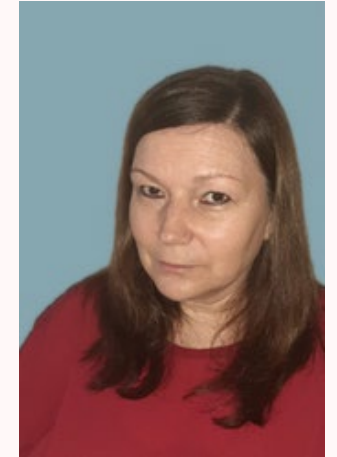


Astrid
Diederichs

Social Media



Cynthia
Focken-Bahmann



Adelheid
Welter

Misceancelous: and Judith Schachtmann





Mission

- Mutual support of affected people and their families.
- Informing practitioners, therapists, carers, teachers, school administrators.
- Advocacy and creating awareness.

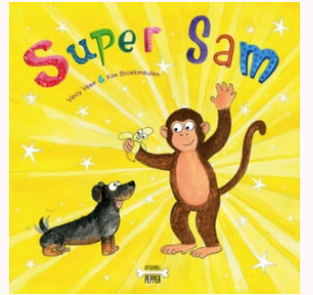
Financing

- Donations and financial support by governing body of German health insurers (Krankenkassen)
- 2021/22: Amazon Smile.



Activities 1/3

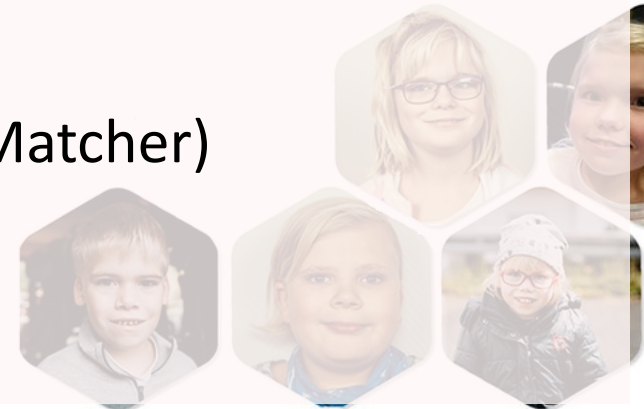
- Information material on diagnosis and therapies for those affected, parents/carers, medical personnel and teachers:
 - [Website](#),
 - Flyers and Brochures,
 - [Videos](#),
 - [Super Sam](#) (German translation and print of Vincy Veen's book),
 - SMS Song "[Helping Hand](#)" by Anke Sheer.
 - 2021: Distribution of flyers to all specialist medical centres in Germany dealing with children with SN.
 - 2021: Articles in various newspapers.





Activities 2/3

- Annual national conference:
 - Presentations by therapists: Cor Reusen, Erik Stork
 - Researchers: Dr. Georg Schwabe, Dr. Wiebe Bram, Heidi Nag (2022)
- *In 2023: 20th anniversary of national conferences*
 - *Key speaker: Ann Smith &*
 - *Dr. Georgie Agar, Dr. Caroline Richards (Cerebra NetworkUK)*
- Annual 'virtual Talks-Saturday' (started in 2021)
 - Dr. Georg Schwabe, Dr. Hellen Lesmannn (GestaltMatcher)
- Regional meetings





Activities 3/3

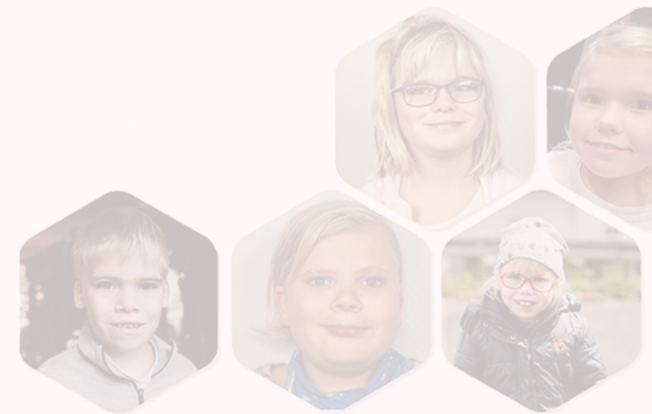
- Newsletter (biannual)
- Birthday mail for SMS people.
- WhatsApp groups (by age group)
- Facebook & Instagram
- Feb/Mar 2022: Sirius joined the Rare Disease Run (Syngap Elternhilfe e.V.)





Membership & Partnerships

- [ACHSE e.V.](#) (alliance chronic diseases)
- [Kindernetzwerk](#) (umbrella organisation for parent support groups in Germany)
- Partner of PRISMS
- Bundesverband Autismus
- SMS-organisations Netherlands, UK...





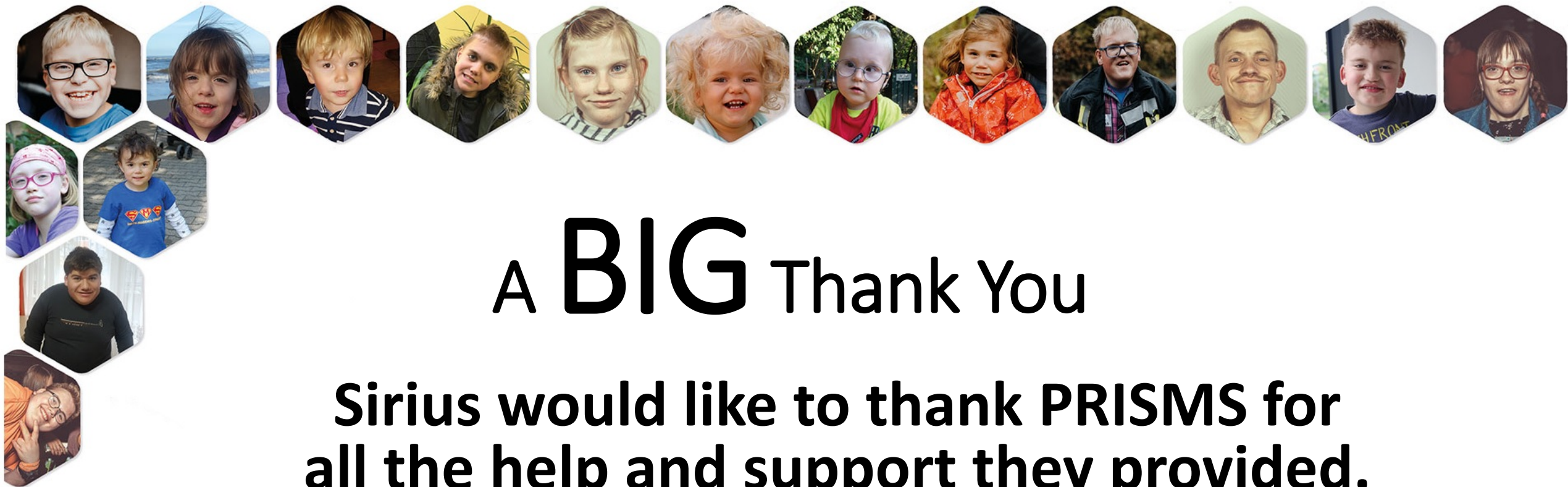
Future (?)

- Creation of a SMS community on www.rareconnect.org
 - Reach non-English speaking people.
 - Extend reach for researchers wishing to collect data for SMS related research.



Future (?)

- Improving coordination of research efforts by support groups world wide.
 - (Bi)annual virtual meetings of professional/academic board?
 - Joint database of SMS data:
 - Small number and privacy issues
→ research data on SMS is usually not published.
 - Solution: SMS data repository:
 - Only variable definition and coding is publicly available.
 - Researchers submit code to run data analysis.
 - Analysis is run by data comptroller.
 - Researchers only receive result.
 - Allows for research on combined data from various studies.



A BIG Thank You

Sirius would like to thank PRISMS for all the help and support they provided.

Astrid Diederichs (a.diederichs@smith-magenis.de)



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May be **SEE You** in Lahnstein next year ... ?



sirius ★ ★ ★

<http://www.smith-magenis.de/>

