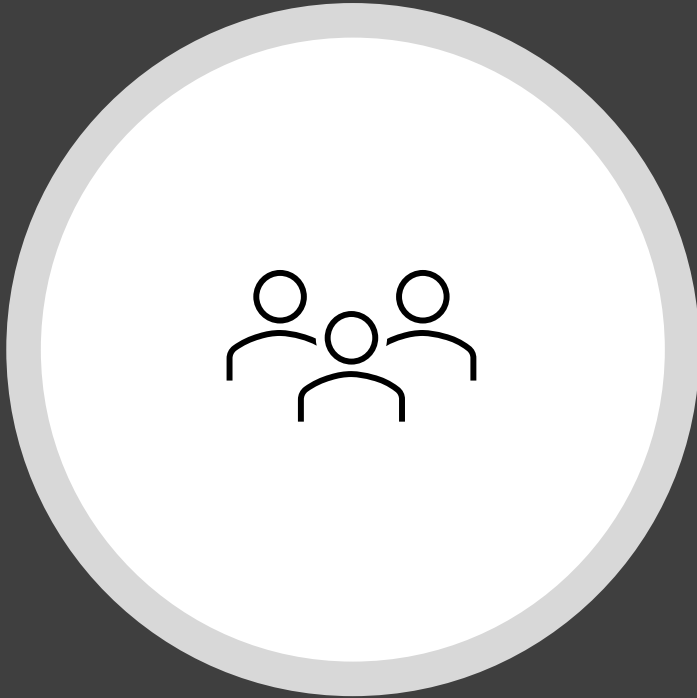




# NAEVUS GLOBAL

Best Practices

Dec 2020



Help Families  
find info



Inspire to  
initiative



Motivate to  
Re-visit site

# Information Center

# Information Center

## ***Nævus Global (Marjolein):***

Collected videos, leaflets, a list of (children's) books, or books written by people with CMN.

<https://naevusglobal.org/books/>

<https://naevusglobal.org/leaflets/>

<https://naevusglobal.org/video-gallery/>

## SEO values

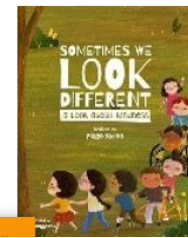


**HOW DO YOU C ME NOW?** Caring Matters Now and Brock Elbank, 2020

Caring Matters Now has produced the HOW DO YOU C ME NOW? photographic book to celebrate the beauty and lives of all those affected by CMN and inspire the world to embrace visible differences; giving a clear message; love the skin you are in!

Featured within this beautifully presented hardback book are 30 portraits of inspiring children and adults affected by Congenital Melanocytic Naevus (CMN), along with personal stories and coping strategies which aim to improve the self-esteem and confidence of anyone living with any visible difference.

'HOW DO YOU C ME NOW?' is a beautiful coffee table book to have at home and, can also be used as an inspiring resource in schools or workplaces for encouraging all ages to embrace their uniqueness, as well as stimulating positive discussion about visible differences.



**Sometimes We Look Different,** Paige Byrne, 2019

Here's the story behind the story: This book was written by a mom of two cuties born only 1.5 years apart. Her second child was born with a large mark called congenital melanocytic nevus covering a large part of her face. The parallels of having a child born without and then one born with a visible difference inspired the creation of this book. As a person who never had to face the world looking differently than her peers, it was eye-opening to experience the stares, comments, and interactions that came with a visible difference. The purpose of this book is to bridge that gap taking a very kid-friendly approach to explain visible differences,



Life with a Diagnosis | Chloe's Messa...



Undergoing Tissue Expansion: Chloe'

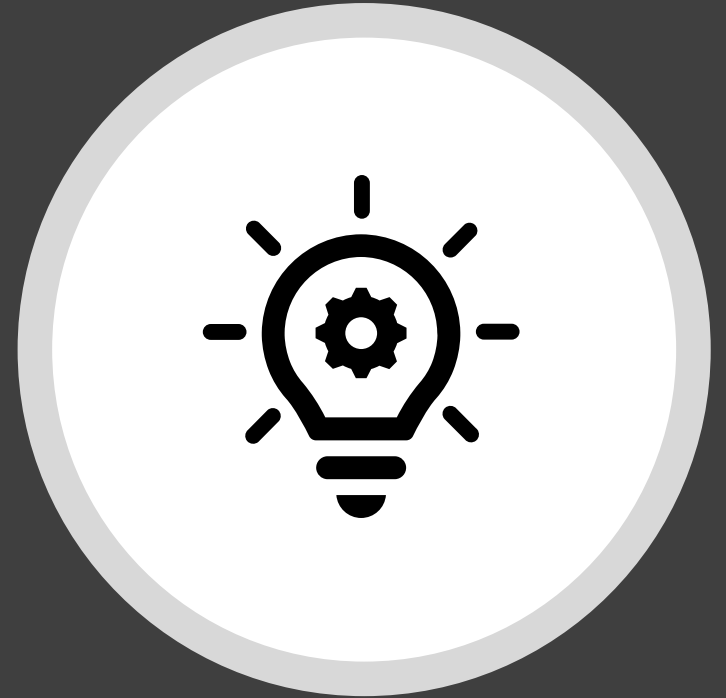
Translate »



Recognition of the  
medical community



Increase  
Donations



Increase knowledge  
of patients

# CMN Research

# CMN Research

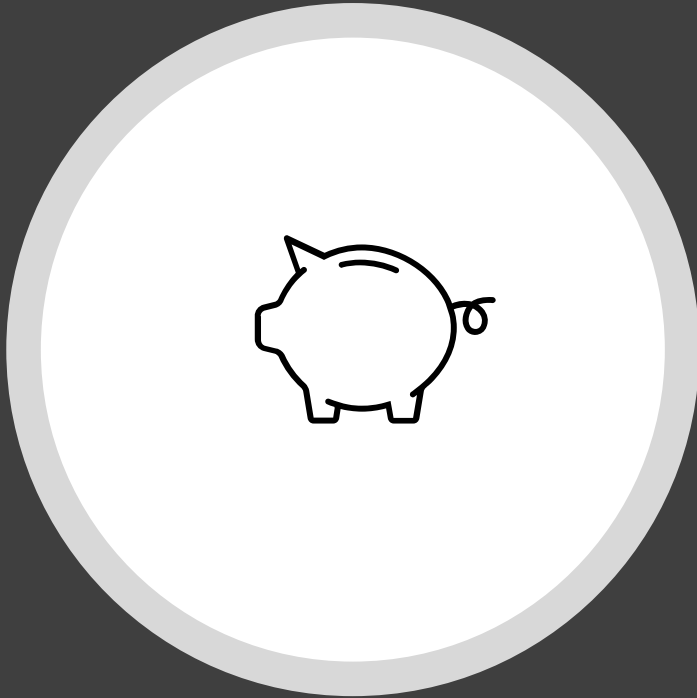
**NL .(Anne):**

- Operate or not to operate

**Children Of Light.(Inbal ):**

- Satellites characterization
- Mental affect of multi surgeries





Families Wealth



Organization  
Reputation



Increase Rights &  
quality of life

# Institution Recognition

# Institution Recognition

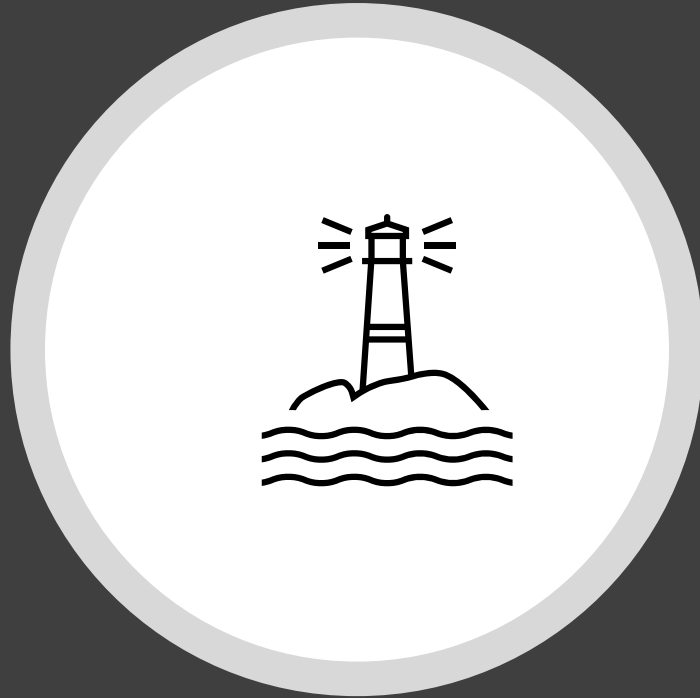
## **Children Of Light.(Inbal):**

Settling the rights of the CMN families with the government offices

- Social security – Monthly disabilities granting in the operations period
- Vehicle Licensing Bureau – Mobility handicap badge
- Legal consulting- to receive the rights



Increase  
Donations



Increase  
Awareness



Community  
Involvement

# Selling Points Events



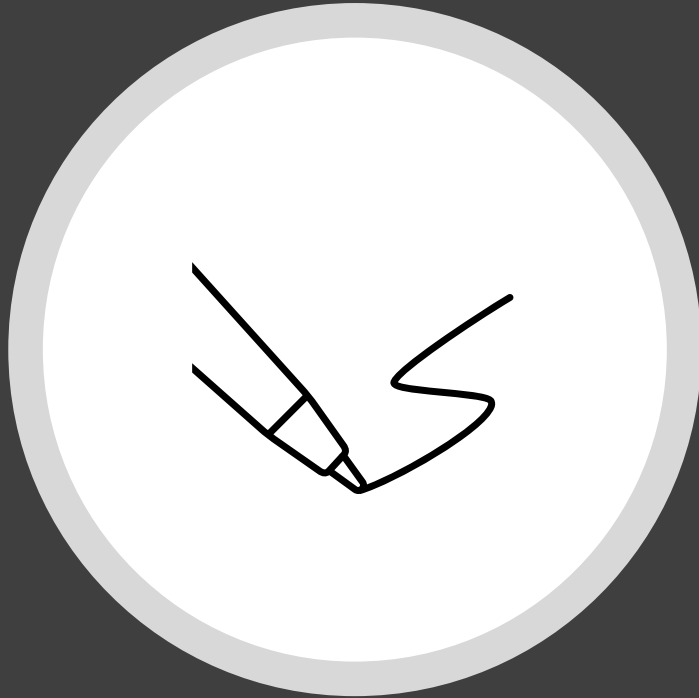
# Selling Points Events

## Children Of Light.(Inbal):

For the last 3 years we have taken “Hanuka” – The Jewish holiday of light, as our organization symbolizing

- Schools are volatizing to pack boxes of toys and sell them
- Lectures are given among the schools about CMN and our organization
- Yard sale and donations, granting 30% of our budget!





Learn from  
other's



Stronger  
Together



Greater  
Achievements

# Sharing Is Caring

# Sharing Is Caring

## Nävus Netzwerk Deutschland e.V.(Benjamin):

Collaboration with other rare disease organizations the country. We have a umbrella organization.

- Contact to lots of other rare disease organizations.
- Use some kind of infrastructure
- Share wisdom / best practices together and have in most cases the same aims- such as raising funds

## All of us 😊



Australia



France



Portugal



Belgium



Germany



South Africa



Brazil



Israel



Spain



Czech Republic



Italy



UK



Columbia



Netherlands



USA



**NAEVUS**  
**GLOBAL**

**Challenges**

# Challenges

- Covid 19 challenges
- Active board: Initiatives, acting and meet deadlines
- Requests for subsidizing medical procedures
- Reaching some patient sectors
- Medical teams' cooperation to increase awareness
- Translations
- Managing support group while having a full life
- CMN pictures