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Dear Friends of Charlie Braveheart,

At this extraordinary time, it does feel a bit strange to send a newsletter when there is this devastating war in Ukraine. The suffering that comes with it is having such a terrible effect on the entire country, not to mention the children who are affected and traumatized by it. While the initiatives that Charlie Braveheart focuses on are of an entirely different order, we felt we should give you an update on the initiatives that Charlie Braveheart has been working on over the past year.

Organisations receiving support from Charlie Braveheart:

 The PROSA foundation is the centre of expertise when it comes to providing education to healthcare professionals and supporting implementation in the field of preventing fear, pain and the use of restraint. It utilises both non-pharmacological and pharmacological methods.



www.prosanetwork.com

 Skills4comfort is a company that specialises in teaching hypnotic language and is an expert centre in hypnosis and non-pharmacological techniques.



www.skills4comfort.nl

 K&Z (Children and Hospital) is a foundation that has fought for and defended the rights of the child for 40 years. They are helping to raise awareness for the mission of Charlie Braveheart to provide care that is free of fear, pain, and avoids the use of restraint. https://kindenziekenhuis.nl/



 Princess Maxima Centre for Paediatric Oncology is the centre in the Netherlands for treatment and research in the field of paediatric oncology.

PROSA-expertise centre, from fear to trust

Courses were organised through the PROSA expertise centre in September and October 2021 and March 2022 to provide insight, knowledge, and skills to professionals about effective prevention and treatment of pain and the prevention of fear and the use of restraint. A website and digital learning environment were also developed to facilitate preparation for the 3-day courses.



Participating hospitals are Amsterdam UMC, UMCG,

WKZ, Kinderthuiszorg (Home care for children), OLVG, Maasstad hospital, Erasmus UMC, Martini hospital, Zuyderland hospital, OLVG, MUMC, Isala, Catharina, AZ-Brugge.

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Storytelling

Stories like those mentioned here show that PROSA's initiatives can work in daily practice through people that attended the basic courses.

Small initiatives often start in their own working environments.

Intervision

To continue building a learning network, after the 3-day basic course is attended, Intervision meetings are organised by the PROSA centre. In these meetings, case-based discussions, with the focus on learning from each other, are the

main objective (with due observance of privacy laws and regulations)

She used the one voice method, dimmed the lights, stroking one arm, didn't warn her of the injection that was to come. Everything was phased and organised in such a way that peace was created, and the girl could undergo the procedure free of fear, trustful and feeling relaxed.

An anaesthetist did everything in her power to provide a

tailor-made solution for a girl with a developmental delay. She motivated the present staff of the OR team by

organising the time out procedure in the busy OR in a

very different way - by talking with a child rather than

talking over the head of a child with an entire team.

Development of educational materials

Several tutorials have been filmed to share insights with participants, teachers, and former participants. In 2022, this will be used in the European ESPA Webinar, among others.

https://vimeo.com/597269500/b354ce9df9

https://www.prosanetwork.com/nieuws/espa-webinar/

Infographics

In collaboration with the K&Z Foundation and skills4comfort, an infographic about the use of positive and stress-reducing language was made in 2020 and was translated into several languages (English, Arabic and Turkish) in 2021.

Vaccination

With the help of Charlie Braveheart, an infographic was made for parents and caregivers about how a child can be optimally guided through a vaccination.





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Congresses, symposia, and other educational activities

Here are some of the conferences and symposiums to which the faculty of PROSA has contributed, dealing with the subject of preventing fear, pain, and avoidance of the use of restraint.

These contributions ranged from short lectures to workshops

- Refresher course Paediatrics 2021
- Symposium children's nursing.nl
- Oral surgery (NVAMK congress) "help a child in the chair"
- FORTIOR (education institute for people with disabilities)
- Children's Fund

Publications and awareness

Here are some publications contributed to by the PROSA faculty.

- Practical paediatrics
- Acta Pediatrica
- DOQ.nl
- Child & Hospital Foundation

Social media

The PROSA-foundation is active on social media, including **LinkedIn** and Instagram



PROSA-symposium

On 8 and 9 September 2022, the international PROSA symposium will be organised with the support of Charlie Braveheart. Specialists from Europe, Canada and the United States in paediatrics who have knowledge about building trust and adequate pain treatment and sedation will participate.

About 500 to 800 healthcare professionals are expected to be involved in this conference in the MECC in Maastricht.

Skills4comfort

Charlie Braveheart has been supporting Skills4comfort courses in the Princess Maxima medical centre for paediatric oncology and the affiliated Shared Care hospitals for several years now. Specifically, this concerns:

- 4-hour courses on Adapted language & Medical hypnosis.
- 3-day medical hypnosis course specifically for practitioners.
- 2-hour intervision training for professionals of the Maxima children's oncology hospital.

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• Research into the effectiveness of these interventions and how implementation can be optimised.

ImaginAction for children

The MEG foundation is a platform from Stanford University where video and audio materials are freely available. These are especially insightful for children and parents about how pain works, what you can do to control these sensations, and how to practice self-hypnosis. Together with Skills4comfort, one of their videos has been recorded in Dutch and is freely available. Follow this link

https://vimeo.com/639853522/3f2329986c

The K&Z foundation

Focus groups

The K&Z foundation has conducted various studies to gain feedback about the experiences and wishes of children and parents when it comes to preventing fear, pain, and the use of restraint.

This was aided by collecting information from focus groups, so that input could be included in the areas of guideline development, standards and agreeing guidelines.

Infographics and other initiatives

An infographic has been developed about the rights of the child (WGBO).

K&Z, together with Child life specialists, mapped out the challenges in the Netherlands and supported this professional group in strengthening their position as ambassadors for trauma-free care.

Research done by K&Z shows that there is a significant relationship between the extent to which the child and parents are listened to and the extent to which they participate in decision-making, and the 'quality of care experienced in this regard'. Other important factors that positively influenced the "perceived quality of care" were the friendliness of healthcare professionals, information provision and a child-friendly environment.

App-development

An app was developed by Ferring Pharmaceuticals and given to the K&Z foundation to help prevent needle anxiety of injections. This is assisted through an instructional animation/app with relaxation exercises.

It is available in the App store and Google Play.

https://apps.apple.com/nl/app/zoma-zoo/id1472499156

https://play.google.com/store/apps/details?id=com.ferring.zomazoo&hl=nl&gl=US

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COVID policy

The K&Z foundation has asked the government to pay attention to a more child-oriented corona policy, from abolishing the deep nose test, child-oriented test streets and procedures, to understand and ease the psychosocial impact of the corona policy (closing schools) and scaling down childcare.

See also the press releases below:

- https://www.nu.nl/kind-gezin/6171225/kinderen-gaan-zichzelf-twee-keer-per-week-testen-hoe-help-je-ze.html?redirect=1
- https://www.nrc.nl/nieuws/2021/12/03/gezondheidsraad-coronavaccinatie-voor-jonge-kinderen-met-verhoogd-medisch-risico-a4067861

Princess Maxima centre for paediatric oncology

- An Anxiety, pain and stress taskforce has been set up. This is a collaboration between the Psycho-oncology department, Anaesthesia and Pain department and the Child life specialists, that together form the Quality-of-Life Unit.
- A Prima-Pass has been developed, in which our patients and their parents indicate how they prefer to be supported in more general and invasive medical procedures. This Prima-Pass is used in both the Maxima and our shared care hospitals.
- In the past two years, the 3-day Medical Hypnosis course, developed by Arine Vlieger and Carla Frankenhuis, has been offered to professionals from Maxima and our colleagues working in the Shared Care hospitals throughout the Netherlands.

In total, more than 150 professionals have been trained. This has an important spin off on the interventions that are used for anxiety, pain, and stress in the shared care hospitals for children with cancer, but also for paediatric medicine in general.

- A group of professionals from Maxima attended the 3-day PROSA course. Consequently, a multi-year intervention program has now been described. Important elements in this are education about child and family development and particularly contact. It includes positive language use, (cognitive) distracting tasks, the integrated treatment and use of premedication and sedation.
- The setting up of a Vascular Access team in which all professionals work together integrally in the field of anxiety, pain, and stress reduction.

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Thanks to your support, we are making progress, but there is still much to do so we continue to persevere with our mission!

We are very happy with our regular donors. To achieve even more we are happy to expand the group, so if you know someone we can approach and ask to become a donor, we would very much like to hear from you!

Thank you very much indeed for your attention and support!

Wulf van Alkemade

Chairman

Charlie Braveheart foundation

 $\underline{www.charliebraveheart.com}$

