

# NF Kinder Center of expertise

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Neurofibromatosis describes a group of 3 rare, genetic tumor predisposition syndromes: NF1, NF2 und Schwannomatosis. Non of these diseases have an EMA approved drug.

Patients with NF need early diagnosis, full information and consultation, and to be continuously provided with healthcare by an interdisciplinary team, under the supervision of a case-manager. NF patients must be under surveillance for their whole life and often need complimentary therapies.

The NF Kinder Center of expertise is a collaboration of the Austrian patient organization NF Kinder and the Medical University of Vienna. It was established in March 2018. Donations raised by NF Kinder allowed to build the necessary infrastructure to offer optimal support for pediatric patients with NF in Austria. It is the first NF specific medical institution for pediatric patients in Austria.

## Holistic care



### 45 minutes time slots for each patient!

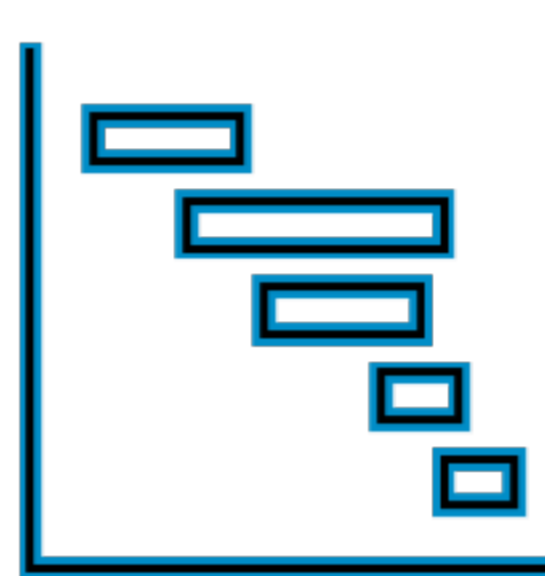
- Case-manager: Neuro-Oncologist/ pediatrician
- Team: Psychologist, social worker, teacher, nurses
- Patient Relations: link to patient organization

#### External collaborations:

- Social competence training <sup>3</sup>
- Hippotherapy <sup>4</sup>
- Music therapy <sup>5</sup>
- Nutrition science department <sup>6</sup> University of Vienna
- Rehabilitation centers

	Number of Patient visits	Total number of patients
2018	456	226
2019	529	254

## Research



### Increased activities!

- Medical and psychological research on a national and international level
- Involvement in international networks <sup>7,8,9,10</sup>
- Longitudinal study since 2016 „Ready for school and work despite Neurofibromatosis Type 1“ <sup>11</sup>
- Attracting young investigators to move into the field of NF
- Establishing a patient registry



## Training



### Building expertise on a national level!

- Regular scientific symposiums <sup>12,13</sup>
- Lectures, Trainings and workshops
- Onsite training for medical doctors and clinical psychologists
- Consulting other clinics
- Lectures in other clinics



## Conclusio

Through this innovative public-private-partnership of the patient organization NF Kinder and the Medical University of Vienna the standard of care for paediatric patients with Neurofibromatosis could be drastically improved, while also boosting research and creating training opportunities, along with expanding the national and international network. The patient organization NF Kinder is able to integrate the patients voice in all aspects of care, research and education. This creates a win-win situation for all stakeholders. The NF Kinder center of expertise is also an associated partner within the ERN GENTURIS

[www.nf-zentrum.at](http://www.nf-zentrum.at)

## References

- 1 [www.pro-rare.org](http://www.pro-rare.org) ; 2 [www.nfkinder.at](http://www.nfkinder.at); 3 <https://www.nfkinder.at/wp-content/uploads/2019/06/Projektbroschüre-Soziales-Kompetenztraining.pdf>; 4 <https://www.nfkinder.at/wp-content/uploads/2019/06/Projektbroschüre-Familienwochenende.pdf>; 5 <https://www.nfkinder.at/interviewpartner-fuer-masterstudie-gesucht/>; 6 [https://www.youtube.com/watch?v=NWEAC7x8\\_io&t=83s](https://www.youtube.com/watch?v=NWEAC7x8_io&t=83s); 7 ERN GENTURIS; 8 NF Patients United; 9 EU PEARL; 10 REiNS group; 11 [https://www.nfkinder.at/wp-content/uploads/2019/11/NF\\_JB2018\\_FitFuerSchule\\_final.pdf](https://www.nfkinder.at/wp-content/uploads/2019/11/NF_JB2018_FitFuerSchule_final.pdf); 12 [https://www.nfkinder.at/wp-content/uploads/2019/06/Abschlussbericht-NF-Tagung\\_End.pdf](https://www.nfkinder.at/wp-content/uploads/2019/06/Abschlussbericht-NF-Tagung_End.pdf); 13 <https://www.nfkinder.at/wp-content/uploads/2020/02/Zusammenfassung-Symposium-2019.pdf>;

