



DECLARATION OF THE NF ACADEMY 2020

Neurofibromatosis (NF) is a chronic, genetic and unpredictable disorder that can be a lifelong challenge for NF patients. We, the „Young voices for NF patients“, ask health professionals and all other stakeholders to acknowledge the huge challenges and unmet needs of NF patients.

Adequate Care Infrastructure

Neurofibromatosis represents a complex set of separate genetic disorders known as Neurofibromatosis type 1 (NF1), Neurofibromatosis type 2 (NF2) and Schwannomatosis. Early diagnosis is of utmost importance for NF patients, as they risk developing medical symptoms and psychosocial issues that can severely impact their quality of life. Recognizing that NF can impact many different organ systems and daily functioning, and due to the fact that there is no cure, comprehensive long-term follow-up-care is essential. Therefore we ask for the establishment of adequate long-term follow-up clinics, where NF patients can have access to personalized care, including long-term follow-up care.

Multidisciplinary Care

Young NF patients require a multidisciplinary approach. We need a specialized NF team that coordinates our care among various specialists¹. Additionally, researchers all over the world need to work together and share their knowledge. Personalized treatment for NF can vary greatly, due to the heterogeneity of the course of the disease. Therefore we need individualized treatments and monitoring plans. We want the opportunity for a shared decision-making approach, together with the NF specialist and the MDT.

Transition Medicine

Without adequate transition from paediatric care to adult care, young adults with NF can easily get lost in the health system. It is of utmost importance that the full medical history of the patients is provided to the new case manager in order to guarantee a continuation of their medical and psychosocial care. Therefore we request that a transition model is in place at every NF clinic.

Rehabilitation Programs

There is a very large number of NF symptoms that can have a severe impact on the quality of life of the patients. The manifestations of NF can require complex - and sometimes extensive - radical surgeries, medical treatments (including chemotherapy), and complimentary therapies. Psychological and mental health issues can also require treatment or therapy. As NF patients can be out of their ordinary life for long periods of time due to these interventions, we highlight the crucial need for adequate rehabilitation programs.

Psychosocial Support

We emphasize the importance, for patients and their family members, of trustworthy and empathetic psychosocial support, both in and outside of the clinic, starting at the moment of NF diagnosis and continuing throughout the patient's entire life. Therefore we ask all treating physicians to take our psychosocial issues seriously and work with a psychosocial team.

Education on reproductive Medicine

Young adults with NF have important decisions to make when it comes to family planning. As new reproductive technologies and screening techniques become increasingly available, we ask the treating clinics to educate patients and families about available reproductive treatments.

Equality

A majority of young NF patients are stigmatized and experience discrimination throughout their life. We ask for equal opportunities in society including, but not limited to, education, employment, and reimbursement of all necessary treatments.

Awareness

Because NF are rare diseases which are not well known to the public, we urge you to work with us to create dedicated awareness programs. We need the solidarity of the public. Everyone should be aware of the risk of a child being born with NF in the next generation of their family. Better treatment options for NF patients should be in the interest of the public.

With the support and commitment of all stakeholders, young NF patients can be actively engaged in society and live their lives to the fullest.

¹ neurologists, surgeons, surgical oncologist, endocrinologist, neurosurgeons, geneticists, therapists and psychologists