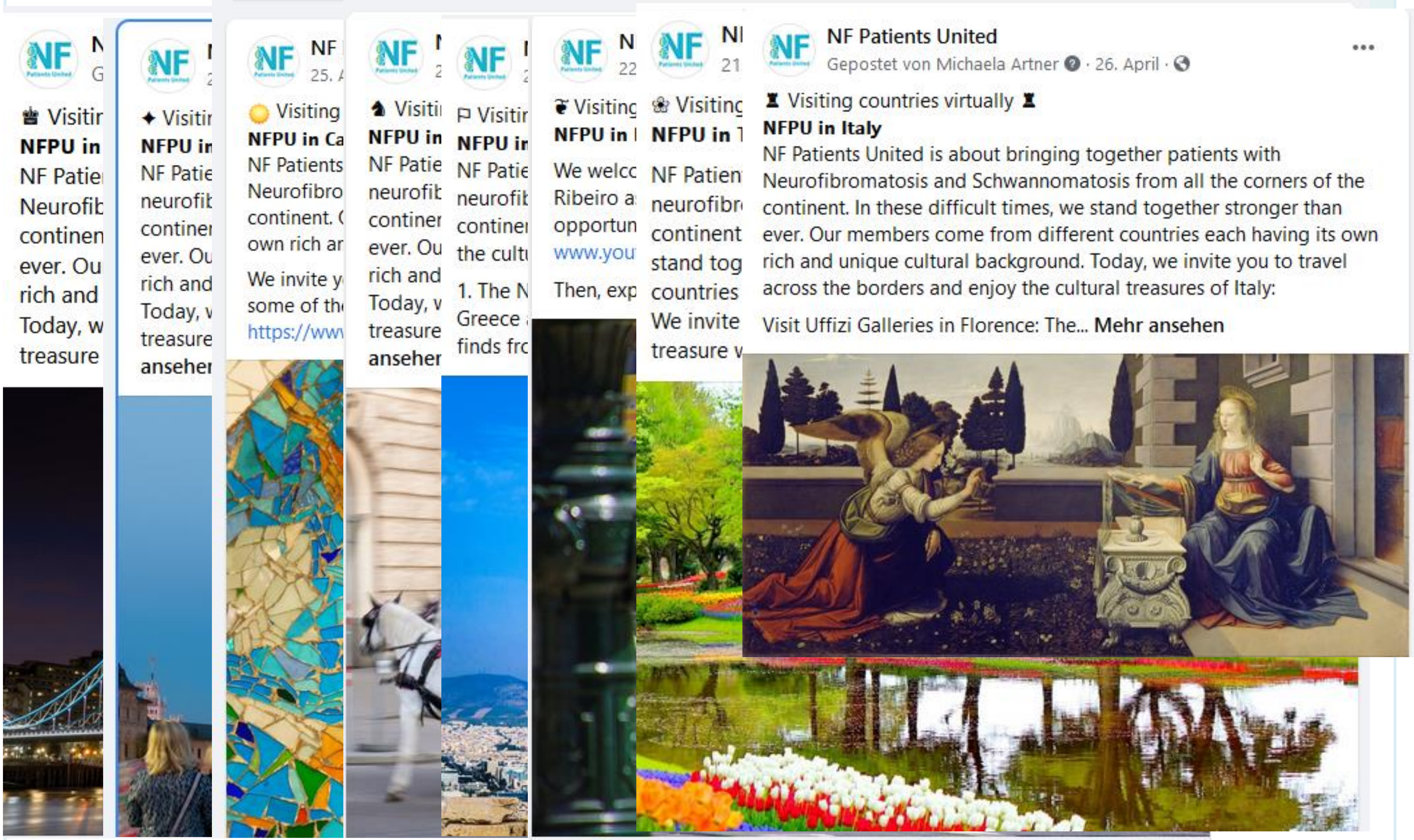
NF
Patients United

Activities

2020

2020 Visit our countries



NF Patients United

Gepostet von Michaela Artner · 26. April

♜ Visiting countries virtually ♜

NFPU in Italy

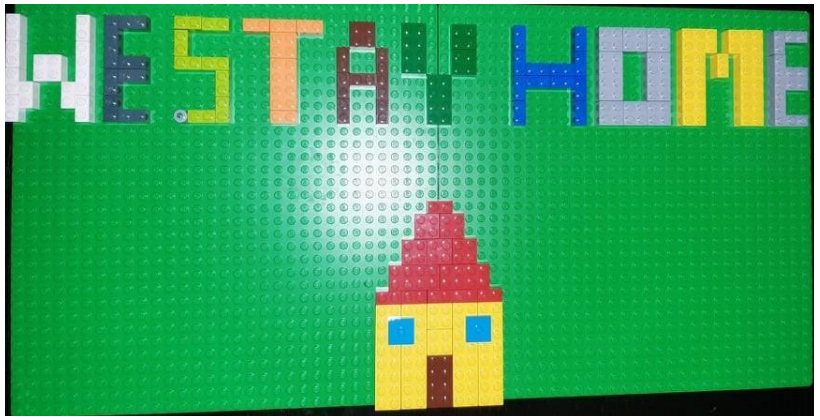
NF Patients United is about bringing together patients with Neurofibromatosis and Schwannomatosis from all the corners of the continent. In these difficult times, we stand together stronger than ever. Our members come from different countries each having its own rich and unique cultural background. Today, we invite you to travel across the borders and enjoy the cultural treasures of Italy:

Visit Uffizi Galleries in Florence: The... **Mehr ansehen**

2020 Corona Creativity

NF Patients United hat ein Video in der Playlist **Corona Creativity** gepostet.
Gepostet von Michaela Artner · 16. April ·

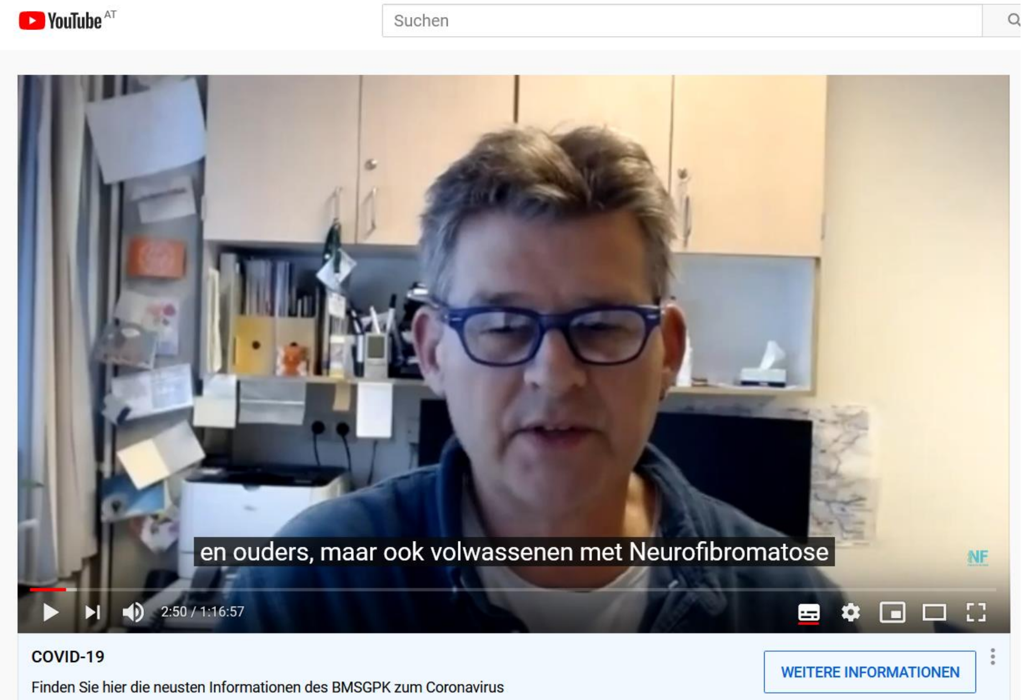
Corona Creativiy
NF Artists from all over Europe:
Pictures painted by NF Russia and
Music performed by Portuguese Association for NF!... **Mehr ansehen**



Info webinars 2020

Webinar „The ongoing COVID-19 situation
for Patients with Neurofibromatosis“
by Dr. Erik Legius
including translation/transcription from members
into these languages: English, Spanish, German,
Netherlands, French and Catalan

people who get really severe symptoms and have to be admitted to the hospital

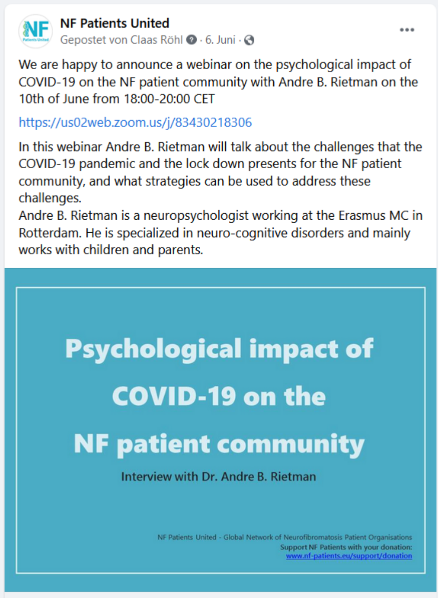


en ouders, maar ook volwassenen met Neurofibromatose

COVID-19

Finden Sie hier die neusten Informationen des BMSGPK zum Coronavirus

Webinar „Psychological impact of COVID-19
on the NF patient community”
by Dr. Andre Rietman
including translation/
transcription from members
into the languages:
English, German
and Netherlands



NF Patients United
Gepostet von Claas Röhl · 6. Juni ·

We are happy to announce a webinar on the psychological impact of COVID-19 on the NF patient community with Andre B. Rietman on the 10th of June from 18:00-20:00 CET

https://us02web.zoom.us/j/83430218306

In this webinar Andre B. Rietman will talk about the challenges that the COVID-19 pandemic and the lock down presents for the NF patient community, and what strategies can be used to address these challenges.
Andre B. Rietman is a neuropsychologist working at the Erasmus MC in Rotterdam. He is specialized in neuro-cognitive disorders and mainly works with children and parents.

Psychological impact of COVID-19 on the NF patient community

Interview with Dr. Andre B. Rietman

NF Patients United - Global Network of Neurofibromatosis Patient Organisations
Support NF Patients with your donation:
www.nf-patients.eu/support/donation

2020 Shine a light on NF from home

Shine a Light on NF from Home

1. Prepare some green or blue dishes

2. Share the recipes and pictures of the meal by using #shinealightonnf or #endnf

Shine a Light on NF from Home

1. Tinker window decorations in the NF colors green and blue

2. Label the artworks with #shinealightonnf or #endnf and share them on Facebook or Instagram

https://www.facebook.com/events/1451243705037770

Shine a Light on NF from Home

1. Organize a small fashion show with your family, wearing green and blue clothing or make-up

2. Share a picture of it with us by using #shinealightonnf or #endnf

NF Patients United

17. Mai ·

#endNF #shinealightonNF #NFPU

Shine a Light on NF from Home

1. Talk to friends and acquaintances about NF to creates awareness

e a Light on

ent

LET'S ALL HAVE A

TEDDY BEAR'S PICNIC

IN SUPPORT OF NF AWARENESS DAY 2020

This year is a bit different because we can't go out and spend time with our family and friends, but Childhood Tumour Trust would still like to spread NF Awareness and have some fun! We are therefore encouraging you to still have a Teddy Bear's Picnic on NF Awareness Day, the 17th of May, but within your own household. We'd love you to take part by having a picnic in your house or garden and sharing your photos with us.

SUPPORTING CHILDREN AND YOUNG PEOPLE WITH NEUROFIBROMATOSIS TYPE 1 (NF1)

Shine a Light on NF from Home

1. Illuminate your home with green or blue light bulbs

Tip: You can also hang a green or blue cloth in front of your lamps.

2. Share a picture of it with us by using #shinealightonnf or #endnf

NF Young Adults Patients Academy 2020

NF Patients United

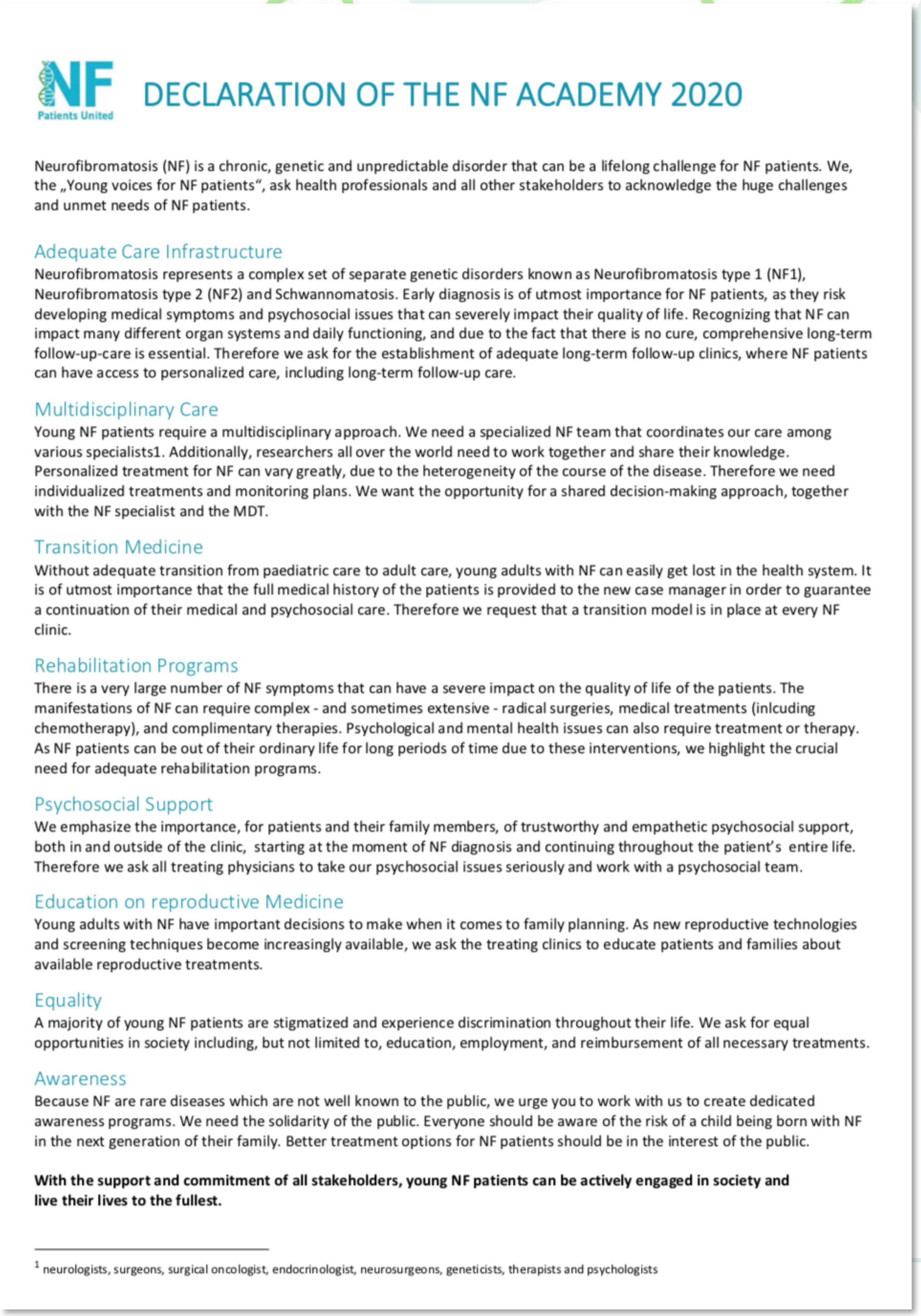
NF Patients Academy

Educating young NF Ambassadors

2020

- Summer school for young NF patients and their siblings or young parents of children with NF (age 16-30)
- Conducted by NF Kinder (Claas & Michaela)
- 9 training modules
- Melpo Pittara joined the NFPU board as the Schwannomatosis patient representative

NF Young Adults Patients Academy 2020



NF Patients United

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 (inlcuding 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.

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

EU PEARL

- Co-development and dissemination of a survey for patient representatives to identify research priorities
- Conducted together by five members from NF Patients United
- Stakeholder workshop - 4 virtual meetings 08,22,26 and 29 October 2020 - more information
- Establishment of a patient advisory group for the duration of the whole project - NFPU involvement through 2 NF Patient United members

NF1 clinical guidelines

- Clinical guidelines on tumor management in NF1
- Conducted by ERN GENTURIS
- Started in spring 2020 - probably will be published mid 2021
- NFPU involvement through: Vera, Maria, Rena, Vanessa, Elis, Claas
- Several virtual meetings, focus group discussions, Delphi survey
- ongoing: lay summary of the guideline

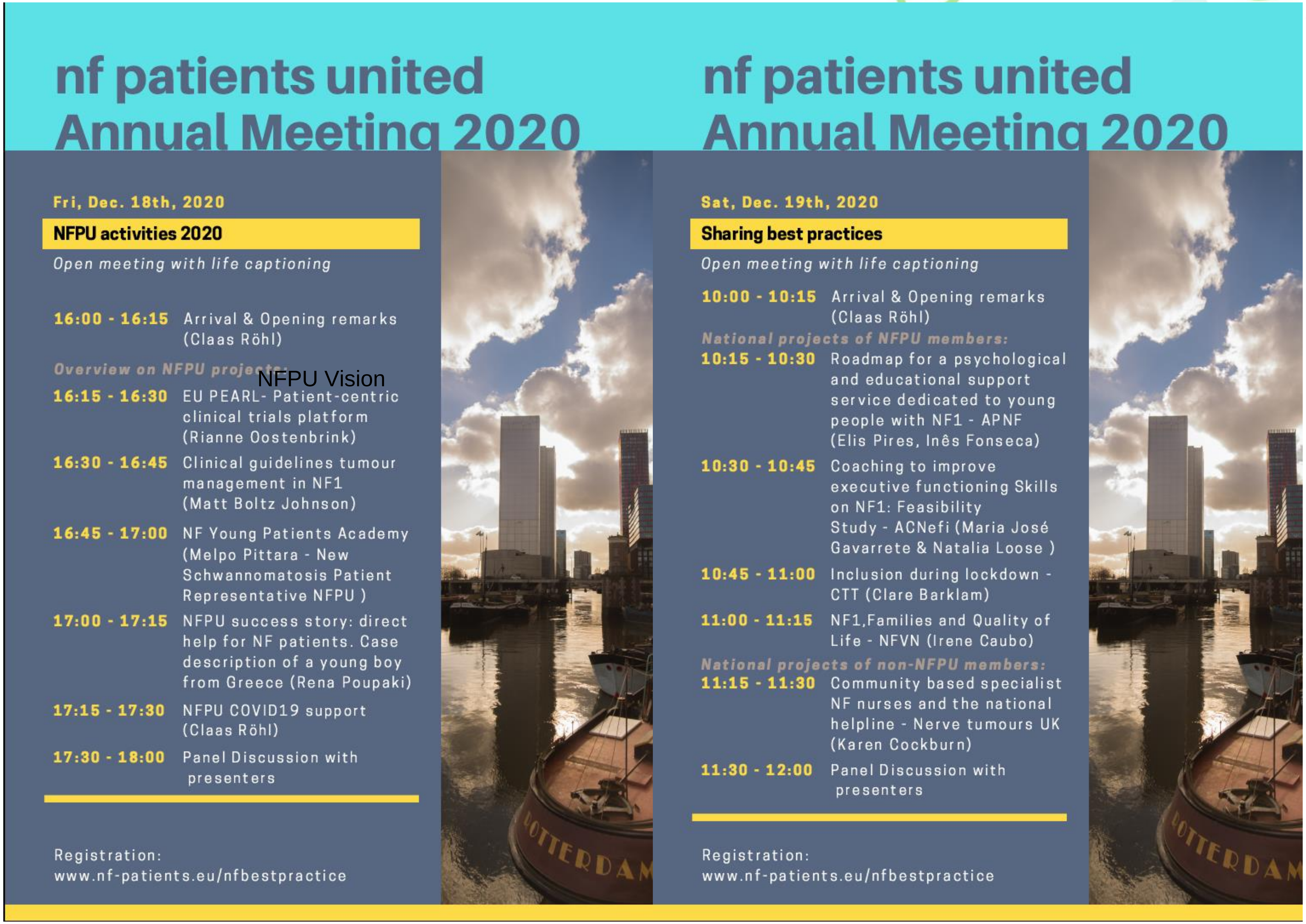
Schwannomatosis clinical guidelines

- Clinical guidelines on Schwannomatosis
- Conducted by ERN GENTURIS
- Started in autumn 2020
- NFPU involvement through: Melpo, Nicholas

NFPU community award

- Premiere at European NF conference last week
- Category NF1 and NF2/ Schwannomatosis
- Jury with NFPU participation selected top 3 research projects which were presented at the public day - the audience voted for the winner
- Award was send to the winners with the request to get a photo back:

NFPU Annual Meeting & Best practice



nf patients united Annual Meeting 2020

Fri, Dec. 18th, 2020

NFPU activities 2020

Open meeting with life captioning

16:00 - 16:15 Arrival & Opening remarks (Claas Röhl)

Overview on NFPU projects:

NFPU Vision

16:15 - 16:30 EU PEARL- Patient-centric clinical trials platform (Rianne Oostenbrink)

16:30 - 16:45 Clinical guidelines tumour management in NF1 (Matt Boltz Johnson)

16:45 - 17:00 NF Young Patients Academy (Melpo Pittara - New Schwannomatosis Patient Representative NFPU)

17:00 - 17:15 NFPU success story: direct help for NF patients. Case description of a young boy from Greece (Rena Poupaki)

17:15 - 17:30 NFPU COVID19 support (Claas Röhl)

17:30 - 18:00 Panel Discussion with presenters

Registration:
www.nf-patients.eu/nfbestpractice

nf patients united Annual Meeting 2020

Sat, Dec. 19th, 2020

Sharing best practices

Open meeting with life captioning

10:00 - 10:15 Arrival & Opening remarks (Claas Röhl)

National projects of NFPU members:

10:15 - 10:30 Roadmap for a psychological and educational support service dedicated to young people with NF1 - APNF (Elis Pires, Inês Fonseca)

10:30 - 10:45 Coaching to improve executive functioning Skills on NF1: Feasibility Study - ACNefi (Maria José Gavarrete & Natalia Loose)

10:45 - 11:00 Inclusion during lockdown - CTT (Clare Barklam)

11:00 - 11:15 NF1,Families and Quality of Life - NFVN (Irene Caubo)

National projects of non-NFPU members:

11:15 - 11:30 Community based specialist NF nurses and the national helpline - Nerve tumours UK (Karen Cockburn)

11:30 - 12:00 Panel Discussion with presenters

Registration:
www.nf-patients.eu/nfbestpractice

NFPU members 2017 - 2020

2017 2018 2019 2020

NF Patients United is:

ACNefi

ananas
ONLUS

NFVN
Neurofibromatose Vereniging Nederland

ANF
Associazione Neurofibromatosi

NFPU Vision

Asociación de Afectados de Neurofibromatosis

NF Kinder

22 17

Ζωή με NF
ΠΑΝΕΛΛΗΝΙΟΣ ΣΥΛΛΟΓΟΣ ΑΣΘΕΝΩΝ &
ΦΙΛΩΝ ΠΑΣΧΟΝΤΩΝ ΑΠΟ ΝΕΥΡΟΪΝΩΜΑΤΩΣΗ

Childhood
Tumour
Trust

NF - foreningen

HRVATSKA UDRUGA ZA NEUROFIBROMATOZU
CROATIAN NEUROFIBROMATOSIS ASSOCIATION

APNF
Associação Portuguesa
de Neurofibromatose

NF Turkey

Schweizerische Neurofibromatose-Vereinigung

NF Patients United

Global Network of Neurofibromatosis Patient Organisations

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