
NF PATIENTS UNITED ANNUAL MEETING 2021



virtual event
on 6.&7. Nov. 2021

Registration: www.nf-patients.eu/nfbestpractice2021/

Saturday - 6.11.2021



12:00 - 13:15 NFPU Annual Meeting 2021
(members only)

Open program (for public)

13:30 - 14:00 Opening Words - Claas Roehl

14:00 - 14:30 NF1 Guidelines - Erik Legius

14:30 - 15:00 NF virtual summit for young patients (U.S) -
Gillian Payne

15:00 - 15:30 Break

15:30 - 16:00 NF Young Adult Leadership Program -
Littlest Tumor Foundation

16:00 - 16:30 NFPU Awareness Campaign 2021

16:30 - 17:00 REiNS - Vanessa L.Merker

17:00 - 17:30 NF2 Reseach - Scott Plottkin

17:30 - 18:00 Schwannomatosis Guidelines -
Ignacio Blanco



Sunday - 7.11.2021

Open program (for public)

National member projects & non-member projects

10:00 - 10:30 The meeting spot, A web app for the NF community - Theo Fernandes (PT)

10:30 - 11:00 Rehabilitation of pediatric patients
- Claas Roehl (AT)

11:00 - 11:30 Supporting parents with diagnosis on NFI
- Rare Minds (GB)

11:30 - 12:00 Artificial intelligence tools in the work of NF patient organisations: Russian case
- Vera Lipovsky (RU)

12:00 - 12:05 Wrap up and Closing Words

Workshop (for members and other patient organisations)

13:00 - 15:00 - New ideas for NFPU projects in the future
- Recent developments and how to get the best out of it
- Presentation of Outcome

Supported by:

AstraZeneca 