



Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

March 16, 2022

Without a doubt, the National Foundation for Ectodermal Dysplasias (NFED) annual Family Conference is the premier event of the year for the NFED. It allows our large and wonderful family to come together to laugh, play, share stories, cry and learn together. The NFED's Scientific Advisory Council (SAC) is excited to have a live, person-to-person conference for the first time in three years, and each of the SAC members is looking forward to sharing their expertise with our families, as well as to learn from the families' experiences.

The key word is family. The members of the SAC are dedicated to assuring our NFED Family Conference attendees are able to experience the conference in the medically safest manner possible. Unfortunately, the COVID-19 pandemic is not yet in our rear-view mirror. While the Omicron variant has substantially subsided in the United States, and the Centers for Disease Control and Prevention has relaxed masking recommendations, new variants continue to emerge. We hope for the continuing decline in cases, hospitalizations and COVID-19 deaths.

Just as in our individual families, it is extremely important our NFED Family does everything possible to protect its most vulnerable family members from exposure to COVID at the Family Conference. Therefore, THE SAC STRONGLY RECOMMENDS THAT ALL CONFERENCE ATTENDEES WEAR A MASK. Mask-wearing will not be mandatory, but highly encouraged. Study after study has shown that wearing a mask significantly decreases the risk of acquiring and spreading COVID.

The Family Conference is greatly enriched by the attendance of children, both affected by an ectodermal dysplasia and unaffected sibs. At this time, children in the United States under the age of 5 years are not eligible to be protected from COVID by vaccination. Many affected individuals at the conference are at increased risk for acquiring COVID and for having a serious outcome, due to either immune deficiency or impaired respiratory function. It is our collective responsibility to protect our vulnerable NFED family members from infection with this horrible virus.

All NFED staff members and all Scientific Advisory Council members will be wearing a mask at all times that they are in a public space, unless they are eating. SAC members will NOT do any person-to-person consultations unless all parties are wearing a mask, no exceptions.

The SAC also STRONGLY RECOMMENDS THAT ALL PERSONS ELIGIBLE FOR COVID-19 VACCINATION AND BOOSTERS RECEIVE THEM in sufficient time before the conference.

Again, this is not a mandatory requirement for attendance, but it is highly encouraged. Just as with masking, the benefits are not only to the vaccinated individual, but are also shared with others in the greater community, in this case the NFED Family.

If you firmly believe that you should not be vaccinated or wear a mask, the Scientific Advisory Council respectfully asks that you please consider skipping the NFED Annual Family Conference this year. We will look forward to working with you at future Family Conferences not marred by a pandemic.

Sincerely,

The NFED Scientific Advisory Council

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