



CONNECT

Coming together to connect as a community was a highlight for participants of all ages and backgrounds.



12 COUNTRIES REPRESENTED

49 FAMILIES

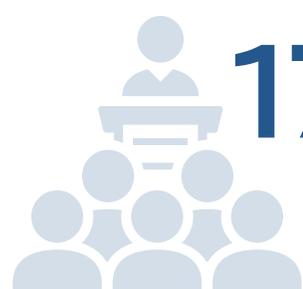
6 FAMILIES BROUGHT EXTENDED FAMILY MEMBERS
(aunts, uncles, grandparents, cousins)

**Members of the [International President's Council](#) met on the opening day of the Family Gathering and participated in sessions throughout the weekend.*

27 PARTICIPANTS UNDER 18 YEARS OLD

LEARN

Families increased their knowledge of disease management and well-being in a variety of topics and settings.



17 SESSIONS

14 BREAKOUT GROUPS

57

MEETINGS WITH AN FOP EXPERT

29 ASK A DOCTOR

28 ASK A DENTIST

Attendees partnered with researchers to advance what we know about FOP.



43 PATIENTS & FAMILY MEMBERS DONATED SAMPLES TO THE IFOPA'S [NEW FOP BIOBANK](#)

26 BLOOD SAMPLES
34 URINE SAMPLES
42 SALIVA SAMPLES

7 ANCILLARY RESEARCH MEETINGS



11 UCSF MICROBIOME STUDY KITS DISTRIBUTED

GROW

Participants shared what they loved about the Family Gathering and the way the community is growing together.

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Meeting other families in the same situation, learning from one and other, and seeing the positive.

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Being one in two million, but feeling like two million friends gathering together!

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I felt like I was with my family. A new family that knows about the path I am walking with my child and are there to make me feel that I am not alone.

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I was most grateful to learn about the disease and to connect with other families. It felt like, together, our family meeting was getting closer to a cure!

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The fact that my child was able to connect with other FOP'ers and realize he is not alone was invaluable. I'd travel high and low to have that experience again and again for him. It's the most important thing when you have a rare disease that you feel not alone and are able to connect with other people your age.

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To put faces with names of people I've been communicating with via email & Facebook for some time!

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TAKE A LOOK! The photo gallery for the 2018 Family Gathering can be viewed [here](#). Check back on the [website](#) soon for access to recorded presentations from the event.