



## **Resilience Education: Supporting the emotional well-being of those with a progressive disease**

There were valuable lessons learned during the past year and a half of piloting the Resilient Living Program. As staff, the IFOPA has realized what a tremendous resource it is to provide education and awareness around mental health and the emotional well-being of all members of the community. This had led to increased programming for the different personas in the community, including, for example, a more targeted support for siblings of individuals living with FOP, caregivers and family members of deceased individuals with FOP.

Although we see real benefit to providing these resources to families, we know that they come at a cost in the time trade-off that the participant gives to receive them. To be most effective we are working to provide as much content in small, easy to digest formats and across multiple platforms. In an effort to keep fresh content in front of our community, these social media posts include collaboration with new providers and organizations focused on resilience. Our social media post on the topic of energy medicine - which was delivered written, in video, via webinar and in-person - is one example of this.

The third significant finding has been to provide recurring opportunities to engage in absorbing content. One participant from the Family Gathering attended the pre-conference workshop, morning meditations and nature walks and the afternoon breakout sessions. Another community member who has watched the webinar and attended the workshop also participated in the Resilient Living Educational series. These individuals drive home the point that you can never have enough opportunities to practice resilience. Resiliency is not a skill that you achieve in fullness. It is a trait that you practice across your lifetime, and our families need added support to have opportunities to learn and practice these skills consistently throughout the year.