The Resilient Living Program:

Energy Medicine (self

Social connection and enjoyment (self

Some concepts will be most effectively applied when specific connections are made to the FOP

By providing training opportunities at multiple levels of community involvement in a small, close

Resiliency Resources were shared with the community:

Most training and resources to date have targeted adult education.

Sibling day/ Brother’s and Sisters Day

10 specific skills and traits to improve overall emotional resilience

By providing training opportunities at multiple levels of community involvement in a small, close

The helpfulness of having access to hard copies of materials to references at one’s own pace

The same concept should be explained in a variety of different ways over time

Continued research and collaboration with other sources

New program content should continue to bring in fresh outside perspectives on integrating resilience

The objective in launching this new program was to increase awareness of the impact chronic stress has

Objective:

The objective in launching this new program was to increase awareness of the impact chronic stress has

Approach:

• IFOPA staff complete the train-the-trainer training through Turning Point

• Trainers received a manual with research, activities/exercises, discussion questions, and handouts

• Community members need repeated exposure to content in a variety of formats.

• Resiliency Resources were shared with the community:
  • Video (introductory webinar)
  • Photo (memes and graphics conveying a single aspect of resiliency)
  • Social Media Messaging (weekly post across social media platforms)
  • Printable Handouts (workbooks, 10 Tips for Resilient Living handout, pediatric activities)

• The same concept should be explained in a variety of different ways over time

• Content came from initial training

• Continued research and collaboration with other sources

• Some concepts will be most effectively applied when specific connections are made to the FOP

• Discussion with participants provides continued insight and perspective that can only be

Acknowledgements:

This work was made possible thanks to a train-the-trainer training provided by Turning Point: A

Global Genes

The 10 Facets of Highly Resilient People©

RESILIENCE EDUCATION:

SUPPORTING THE EMOTIONAL WELLBEING OF THOSE WITH A PROGRESSIVE DISEASE

Learnings from the launch of The Resilient Living Program at The International Fibrodsyplasia Ossificans Progressiva Association.

Introduction:

The International Fibrodsyplasia Ossificans Progressiva Association (IFOPA) provides hope to individuals

and their families through education and support programs while funding research to find a cure for FOP,

a rare genetic condition that causes bone to form in muscles, tendons, ligaments and other connective

tissues.

• The Resilient Living Program:
  • patient and family focused
  • mental and emotional support program
  • education for individuals and their families
  • exercises to practice incorporating skills into daily habit
  • 10 specific skills and traits to improve overall emotional resilience

IFOPA Family Services Manager provided Resilience training to the community in a variety of ways:

• In person Family Gathering Workshop

• Virtual Monthly Resilient Living Educational Series Workshops

• Continued Education for existing community leaders (IFOPA Peer Mentor Program)

Growth in new programs to support community resilience:

• Sibling day/ Brother’s and Sisters Day recognition for siblings of individual’s living with FOP

• Social connection and enjoyment (self-replenishment facet) through the FOP (Friendship Over Pages) Book Club

• Energy Medicine (self-care and

hardiness facets) added to resource library after feedback that some forms of self-care are inaccessible for

individuals and that without an approved treatment many families lack a sense of empowerment in managing

their care.

Qualitative feedback from the community includes:

• The importance of being able to discuss this topic in person or over video with other members of the

community.

• The helpfulness of having access to hard copies of materials to references at one’s own pace

• Confirmation that resiliency education is important for both the individual with the diagnosis and

all members of their support network. Improvement in the resiliency of any one members leads to

improvement in the resiliency of the network as a whole.

Figure 1: Source: Turning Point’s The 10 Facets of Highly Resilient People, Training Curriculum

Results:

IFOPA Family Services Manager provided Resilience training to the community in a variety of ways:

• In person Family Gathering Workshop

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individuals and that without an approved treatment many families lack a sense of empowerment in managing

their care.

Figure 2: An overview of the reach of different resiliency programs throughout the

last year and a half.

Next Steps

• New program content should continue to bring in fresh outside perspectives on integrating resilience

into day-to-day challenges and living. Continued collaboration with outside organizations is vital.

• Resource sharing with international communities comes with many challenges (communication via

translation, cultural competency of concepts) but for many communities the need is still there.

• Continued engagement in the Resilient Living Program content through in-person and social

activities (book club) seem to be preferred. Future program development within the Family Services

area will ensure their structure include opportunities to insert resiliency education

• Most training and resources to date have targeted adult education.

• In 2021 the Resilient Living Program will offer its first in-depth resources for a pediatric training.

Figure 2: An overview of the reach of different resiliency programs throughout the

last year and a half.