



QUARTER 4 TOPIC:

Advocating for Mobility & Independence

RESOURCE WORKBOOK CHAPTER



LISTEN to our Advocacy Series Podcast for Quarter 4

Advocating for Mobility and Independence at: ifopa.org/advocating_for_mobility_and_independence



LISA GILLOOLY Living with FOP often requires compromise. But mobility, independence and getting out in the community are all still possible with a little creativity, help from others and a can-do attitude.

Lisa Gillooly's daughter Sara was diagnosed with FOP when she was seven months old. That was more than 30 years ago. Lisa explains how she and her family – who today, you might consider “FOP trailblazers” – advocated for Sara at a time when little was known about her condition. From enrolling her daughter in pre-school to allow Sara the opportunity to learn her limits and abilities on her own to continuing beloved family camping trips to modifying tools and equipment, the Gillooly family encourages Sara to live life to the fullest while coming up with innovative solutions to help. Lisa urges other families not to be afraid in their FOP journey and shares helpful tips and lessons learned throughout theirs.

Family traditions, like an annual camping trip, are so important – not to mention, a lot of fun. What's a special tradition you can start or modify to ensure quality time with loved ones for years to come?

Family Activities We Could Do With Modifications

► SUPPLEMENTAL PODCAST RESOURCES

Finding funding assistance for adaptive technology can be one of the most challenging aspects of getting the equipment you need. It will take effort on your part to do the research – no one is going to do the work for you and that can be intimidating. Get started with a few of the following resources and build your own resource list from there!

- The Assistive Technology Funding Resource Guide at atia.org/at-resources/what-is-at/resources-funding-guide which includes links to various disability-oriented organizations, RESNA, Medicaid, Medicare and Waiver links, and state and federal programs in the United States.
- Vocational Rehabilitation Services: disability.gov/resource/vocational-rehabilitation-state-offices
- eSpecial Needs Funding Resource Links: especialneeds.com/funding
- The Christopher Reeve Foundation: christopherreeve.org
- Help, Hope, Live: helphopelive.org
- MedGift: medgift.com



Websites And Agencies In My Community To Contact For Help With Funding

When pursuing equipment to help you maintain your mobility and independence you will inevitably hit roadblocks. Lisa's perseverance to overcome her family's roadblocks are an inspiration for the rest of us to keep relentlessly pursuing needed equipment. Use the space below to draw or list a few reminders, quotes, stories or mantras that you can use to inspire and motivate yourself on your advocacy journey when faced with your own roadblocks:

Inspiration I Need To Keep Pursuing My Needs

COMMUNITY PANEL RESOURCE NOVEMBER 2021



Living with FOP presents unique challenges. Special tools, equipment and strategies for daily tasks can help. With some creative thinking and a problem-solving mindset, people with FOP can improve mobility to maintain more independence and build confidence.

Three members of the FOP community share solutions – for themselves or someone they love – to live more independently. Kristi Gonzales, mom of AJ, never wants parents to think their kids can't take part in something because of a condition. She explains how AJ remains independent and active in and out of the household. Emma Albee and Laurent Gouy have FOP. They share the tools and modifications that help them get around their homes and engage with their communities.

Ultimately, finding what works for you is a trial-and-error process. Our panel of mobility and independence advocates offer lessons and inspiration to explore new ideas.

You can watch a recording of the community panel resource at ifopa.org/advocating_for_mobility_and_independence



KRISTI GONZALES' 11-year-old son AJ was diagnosed with FOP more than eight years ago. Since then, Kristi and her husband have worked hard to give AJ his independence. She acknowledges that trying new tools can be intimidating and frustrating, but it's worth the effort. Kristi shares how AJ remains independent at home and at school. She also explains how it was important to pursue adaptive sports to help with AJ's confidence, mobility and overall fitness. She feels adaptive sports have made AJ feel included – and provide a healthy dose of competition and fun.

What school modifications or adaptive sport activities did Kristi mention that you hadn't considered?

Additional Notes:

Start a list of the ones you would like to pursue and prioritize which one to tackle first!

- 1

- 2

- 3

- 4

COMMUNITY PANEL RESOURCE NOVEMBER 2021



EMMA ALBEE, 32, was diagnosed when she was nine years old. Her condition progressed quickly, and she was in a wheelchair within a year. But FOP didn't stop Emma from going away to college to earn a degree in medical biology. Today she works at Acadia National Park and relies on all kinds of tools to make it easier to get around her home and office. Emma insists it's about the little details - finding creative solutions to overcome seemingly small obstacles can make a big difference.

Resourcefulness is key when adapting to changing mobility. Sometimes there are better ways to take advantage of a tool than its intended use. (For instance, using a toothbrush to clean behind your ears.)

Consider what items you already own. Are there creative ways to use them to solve a challenge you're facing?

ITEM

NEW USE



LAURENT GOUY, 56, lives in his partially adapted apartment in Nantes, France. Although he was diagnosed at the age of 10, it wasn't until flare-ups occurred as an adult that FOP really started to affect his mobility. Today he is in a wheelchair. Several clever solutions help him maintain independence and help his caregivers complete tasks more easily. Even with his limited mobility, Laurent is determined to continue the activities he loves. He shares how he stays engaged with his community, including through a unique adaptive hobby he practices regularly – and is quite good at!

A hobby is a great way to have fun, let off steam and develop a new skill.
What activity have you been wanting to try? Consider setting aside time each week for it.

Additional Notes:

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Mary Hamell, COTA/L, ATP



Nancy Sando,
FOP community member

We end our Advocating for Mobility and Independence topic with a resource webinar about the wheelchair evaluation process. For those living with FOP, a power wheelchair will likely be the largest and most important mobility device you will own. If prescribed and used correctly, it can return a sense of independence to an individual once FOP has taken away their body's anatomical mobility.

In this webinar, Mary Hamell, COTA/L, ATP and FOP community member Nancy Sando share tips and strategies that are important when preparing for a power wheelchair evaluation. Mary covers important considerations when planning for your first wheelchair, the assessment process, and how to advocate for the wheelchair options you may need to result in a well-configured seating system. Nancy Sando additionally shares her custom-molded cushion experiences and why this type of cushion is best-suited for her body and FOP.

WATCH a recording of our Advocacy Series Resource Webinar for Quarter 4
Advocating for Mobility & Independence at
ifopa.org/advocating_for_mobility_and_independence

YOUR WHEELCHAIR AND SEATING SYSTEM IS REALLY AN EXTENSION OF YOU!

It is an extension of the skills you have gained over your lifetime and the mobility you still have, and it is vital to have a thorough wheelchair evaluation to maintain those skills and mobility.

- MARY HAMELL COTA/L, ATP

KEY TAKE-AWAYS FROM THE WEBINAR

- 1** An inappropriately configured wheelchair can result in negative consequences to one's physical functioning including skin breakdown, breathing difficulties, digestive issues, and poor comfort, safety and quality of life. For this reason, it is important to prepare for your wheelchair evaluation ahead of time and speak up during the eval if your opinion isn't being considered or the chair configuration doesn't include something you need.
- 2** Educate yourself ahead of time! Call your insurance company and find out your coverage for power wheelchairs. Ask others in the FOP community what wheelchairs and cushions have worked for them and what features they have found to be either useful or unnecessary. Research the major wheelchair brands and the different equipment features each company offers. Check out a few of the websites on the following worksheet pages to get you started!
- 3** Insurance companies require substantial documentation during the process of obtaining a power wheelchair. Unfortunately, most requests are denied the first time around, but **DON'T LET THAT STOP YOU!** Keep fighting for what you need – refusing to give up is what being an advocate is all about. You will need to be in the driver's seat for gathering the additional documentation that is needed for an appeal – ask your doctor, therapists, wheelchair evaluation team and DME vendors to help you with this process.

Continued on next page

- 4 There are 3 different types of “drive styles” for power wheelchairs: Rear-Wheel, Mid-Wheel and Front Wheel. Each of these styles have their own pros and cons, so it is important to understand the difference between them to help determine which drive style will better meet your needs. It is also wise to “test-drive” each type to see how well you handle the different styles.
- 5 Cushions are a very important part of the seating system and should not be an afterthought. “Off-the-shelf” commercial cushions are relatively inexpensive, but they are not individualized and don’t provide the best support or cushioning where you may need it. Even a more customizable cushion, such as cushions with air-filled chambers that can inflate or deflate in specific regions, still may not perfectly conform to the body of someone with FOP. Determine if your insurance will cover a custom-molded cushion which is perfectly molded to your body shape and can provide better comfort and protection of your pressure points. You will be spending a significant amount of time in your seating system and should advocate for the highest quality cushion available.

My Notes on the Presentation:

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How To Effectively Advocate AT YOUR WHEELCHAIR EVALUATION



1 RESEARCH MAJOR WHEELCHAIR BRANDS Take the time to learn the different equipment features each company/vendor offers. Make a list of must-have features and accessories to bring with you to your eval. Check out a few of the following websites to get you started!

INVACARE Power Wheelchair Models rehab.invacare.com/Power-Mobility

INVACARE Cushion Systems rehab.invacare.com/Seating-Positioning

INVACARE Mobility Device Guide: www.flipsnack.com/7b55c7ec5a8/onemobility-final0311/full-view.html

QUANTUM www.quantumrehab.com

PERMOBIL Main Website: www.permobil.com/en-us

PERMOBIL Seating & Positioning: www.permobil.com/en-us/products?category=PowerWheelchairs

PERMOBIL Handbook: The Consumer's Guide to Seating and Mobility Equipment fs.hubspotusercontent00.net/hubfs/1624307/Academy%20Resources/The%20Wheelchair%20Handbook.pdf

QUICKIE Main Website: www.quickie-wheelchairs.com

QUICKIE Power Wheelchairs: www.quickie-wheelchairs.com/Quickie-Power-Wheelchairs/552c0

QUICKIE Cushions and Backs: www.quickie-wheelchairs.com/Wheelchair-Cushions-Backs/603c0

QUICKIE Parts and Accessories: www.quickie-wheelchairs.com/Wheelchair-Parts-Accessories/1276c0

2 PRE-AUTHORIZE WITH YOUR INSURANCE Make sure to call your insurance company, Medicare, Medicaid or other healthcare agency to verify your benefits ahead of time. Different funding agencies may dictate which clinic locations or equipment vendors you can use for the evaluation. When you call, make sure to ask for:

- ☐ A list of approved seating clinic evaluation sites
- ☐ A list of approved DME/CRT vendors you can use
- ☐ Which wheelchair brands are (or are not) covered under your policy
- ☐ Types of cushions that are covered (advocate for a custom-molded cushion if possible)
- ☐ Your coverage amounts (and what % you may have to pay out of pocket)
- ☐ How often your policy covers a new replacement chair (5 years, 10 years, etc.)

3

FIND A REPUTABLE EVALUATION SITE Determine if your local hospital has a Rehabilitation department or a Seating Clinic. These sites tend to have a team of therapists and certified Assistive Technology Professionals (ATPs) designated solely for wheelchair evaluations who have more experience and knowledge about a larger variety of equipment brands and accessories. Be sure to advocate for an ATP to be on your team. Also ask if they can provide multiple brands and models of wheelchairs and accessories to test out on site. If there is not a Seating Clinic with certified therapists and ATPs near you, consider traveling to a higher-quality facility further away. If that is not possible, call the local wheelchair vendors approved by your insurance coverage to determine the best site for your evaluation.

EVALUATION SITE	PHONE NUMBER	CONTACT PERSON	NOTES (ATP on team? Test a variety of brands on site?)

4

DOCUMENT THE DETAILS OF YOUR DAILY ROUTINES AND ENVIRONMENTS The evaluation team will be able to more successfully prescribe you a customized chair when you provide them with larger amounts of extremely detailed information. If you do not share with them all aspects of your life (both what functions well and what does not), they will not be able to determine the wheelchair features that will best meet your needs, putting you at risk for a poorly configured wheelchair system that decreases your mobility and independence. The following checklist can be used as a guide to prompt which daily routines and environments to document, but you should strive to be even more detailed about the activities you wish to engage in that may not be listed below.

REASON FOR REFERRAL

- ☐ Need wheelchair for longer distances in the community, still ambulatory at home
- ☐ New full-time wheelchair user (New loss of mobility)
- ☐ Current wheelchair no longer meets needs
- ☐ Current wheelchair damaged beyond repair

MOBILITY LIMITATIONS THAT MAY AFFECT CARE

(describe which joints have fused, angles they have fused, as well as balance, strength and endurance concerns):

PATIENT GOALS

CAREGIVER GOALS

DWELLING TYPE AND LOCATION

- ☐ House ☐ Condo/Town Home ☐ Apartment ☐ Assisted Living ☐ Long Term Care Facility ☐ Other _____
- ☐ Own ☐ Rent ☐ Allowed to make modifications
- ☐ Rural ☐ Urban ☐ Suburban ☐ Paved Roads ☐ Rough Terrain ☐ Sidewalks ☐ Curbs ☐ Other _____
- ☐ Live alone/no caregivers ☐ Live alone/caregiver assist ☐ Live with caregivers/family ☐ Hours alone _____

BEDROOM

Doorway width _____ Floor plan/turning radius clearance _____

Flooring: ☐ Carpet ☐ Tile ☐ Hardwoods ☐ Vinyl/Laminate ☐ Anti-slip treatments _____

Ability to safely reach light switches/outlets? ☐ Yes ☐ No

Need ability to raise/lower wheelchair to safely reach these? ☐ Yes ☐ No

Bed position in room _____ ☐ Access to both sides ☐ Against a wall on one side

Bed height _____ ☐ Fixed bed ☐ Adjustable bed

Transfers in/out of bed: ☐ Independent ☐ Assistance from Caregiver ☐ Min ☐ Mod ☐ Max

How do you access clothes? ☐ In dresser drawers ☐ In a closet ☐ Closet has doors ☐ Walk-in Closet

Height of closet rods? _____ Need ability to raise wheelchair height to reach clothes? ☐ Yes ☐ No

Height of windows, blinds and curtains? _____

Need ability to raise wheelchair to open/close them? ☐ Yes ☐ No

Location and floor space measurements where wheelchair can be placed when not in use: _____

Fire escape plan ☐ Yes ☐ No

Emergency call button ☐ Yes ☐ No

Other considerations/questions: _____

HALLWAYS

Width _____ Clearance for turning corners _____

Flooring: ☐ Carpet ☐ Tile ☐ Hardwoods ☐ Vinyl/Laminate ☐ Anti-slip treatments _____

Height of thermostat: _____ Need ability to raise wheelchair height needed to reach items in hall/hall closets? ☐ Yes ☐ No

BATHROOM

Doorway width _____ Direction of door swing _____ Floor plan/turning radius clearance _____

Flooring: ☐ Carpet ☐ Tile ☐ Hardwoods ☐ Vinyl/Laminate ☐ Anti-slip treatments _____

Ability to safely reach light switches/outlets? ☐ Yes ☐ No

Need ability to raise/lower wheelchair to safely reach these? ☐ Yes ☐ No

Sink and mirror height _____ Faucet position _____ Need ability to raise wheelchair for operation? ☐ Yes ☐ No

Leg clearance under sink _____ Exposed hot water pipes? ☐ Yes ☐ No

Measure depth of access under sink _____

Access to toiletries in drawers? ☐ Yes ☐ No ☐ Upper cabinets ☐ Lower cabinets

Need ability to raise wheelchair height to access? ☐ Yes ☐ No

Toilet position in room _____ ☐ Access to both sides ☐ Against wall on one side Toilet height _____

Special seat angle required? _____ Using commode instead of a toilet? ☐ Yes ☐ No Location of commode _____

Require transfer assistance onto toilet? ☐ Yes ☐ No ☐ By caregiver ☐ Mechanical device that raises/lowers

Ability to perform toileting hygiene? ☐ Yes ☐ No Ability to flush independently? ☐ Yes ☐ No

Shower location _____

Transfer into shower independently? ☐ Yes ☐ No ☐ Zero entry shower OR ☐ Water barrier ledge to step over

Roll-in shower chair needed? ☐ Yes ☐ No

Shower chair measurements when fully extended/reclined or in the needed position: _____

Height of windows, blinds and curtains _____

Need ability to raise wheelchair to open/close them? ☐ Yes ☐ No

Location and floor space measurements where wheelchair can be placed when not in use: _____

Fire escape plan ☐ Yes ☐ No

Other considerations/questions: _____

Emergency call button ☐ Yes ☐ No

ADDITIONAL INFO TO CONSIDER:

KITCHEN

Doorway width _____ Direction of door swing _____ Floor plan/turning radius clearance _____

Flooring: ☐ Carpet ☐ Tile ☐ Hardwoods ☐ Vinyl/Laminate ☐ Anti-slip treatments _____

Ability to safely reach light switches/outlets? ☐ Yes ☐ No

Need ability to raise/lower wheelchair to safely reach these? ☐ Yes ☐ No

Sink height _____ Faucet/dish sprayer position _____ Need ability to raise wheelchair for operation? ☐ Yes ☐ No

Garbage disposal switch location _____ Access to dishwasher ☐ Yes ☐ No

Leg clearance under sink _____ Exposed hot water pipes ☐ Yes ☐ No

Measure depth of access under sink _____

Access to food in refrigerator? ☐ Yes ☐ No ☐ Upper cabinets ☐ Lower cabinets

Need ability to raise wheelchair height to access?? ☐ Yes ☐ No

Desire/ability to cook independently?? ☐ Yes ☐ No Desire/ability to grocery shop independently?? ☐ Yes ☐ No

Height of oven/stove top _____ Location of control knobs _____

Need ability to raise wheelchair for operation? ☐ Yes ☐ No

Height of microwave _____ Need ability to raise wheelchair for operation?? ☐ Yes ☐ No

Wheelchair tray or accessories needed to carry food between appliances, counters and table? ☐ Yes ☐ No

Height of windows, blinds and curtains _____ Need ability to raise wheelchair to open/close them? ☐ Yes ☐ No

Height and floor space needed for wheelchair to eat at dinner table _____

Height and floor space needed for wheelchair kitchen island or counter _____

Fire escape plan ☐ Yes ☐ No

Other considerations/questions: _____

Emergency call button ☐ Yes ☐ No

Fire extinguisher within reach ☐ Yes ☐ No

ADDITIONAL INFO TO CONSIDER:

MAIN LIVING SPACE

Doorway width _____ Direction of door swing _____ Floor plan/turning radius clearance _____

Flooring: ☐ Carpet ☐ Tile ☐ Hardwoods ☐ Vinyl/Laminate ☐ Anti-slip treatments _____

Ability to safely reach light switches/outlets? ☐ Yes ☐ No

Need ability to raise/lower wheelchair to safely reach these? ☐ Yes ☐ No

List other furniture you utilize along with height measurements:

Recliner chair _____

Computer desk _____

Game or craft table _____

Food tray table _____

Do you prefer to remain in your wheelchair? ☐ Yes ☐ No Can you transfer to other furniture independently? ☐ Yes ☐ No

List activities you do in main living space:

Watch TV ☐ Yes ☐ No _____

Listen to music ☐ Yes ☐ No _____

Leisure games, puzzles ☐ Yes ☐ No _____

Crafts ☐ Yes ☐ No _____

Read ☐ Yes ☐ No _____

Work/homework ☐ Yes ☐ No _____

Height of windows, blinds and curtains _____ Need ability to raise wheelchair to open/close them? ☐ Yes ☐ No

Location and floor space measurements where wheelchair can be placed when not in use _____

Fire escape plan ☐ Yes ☐ No

Emergency call button ☐ Yes ☐ No

Other considerations/questions: _____

ADDITIONAL INFO TO CONSIDER:

HOME ENTRANCES AND YARDS

☐ Access to front yard ☐ Access to back yard Width of doorways _____ Height of thresholds _____

Ability to safely reach door locks/light switches? ☐ Yes ☐ No Need ability to raise wheelchair to safely reach these? ☐ Yes ☐ No

Height of door peek hole _____ Need ability to raise wheelchair for access? ☐ Yes ☐ No

Can location of peek hole be moved? ☐ Yes ☐ No

Height of mailbox _____ Need ability to raise wheelchair to access mail? ☐ Yes ☐ No

Can mailbox be moved? ☐ Yes ☐ No

Stairs present? ☐ Yes ☐ No How many? _____ ☐ Planning to use a temporary ramp OR ☐ Planning to build a permanent ramp

Ramp incline and length (rise and run)? _____ ☐ Straight ramp OR ☐ Ramp with turns # of turns _____

☐ Ramp has gradual turns ☐ Ramp has tight 90-degree angles Turning radius/clearance? _____

☐ Pitched Yard ☐ Flat Yard ☐ Grass terrain ☐ Rough terrain

List the activities you do, or would like to do in the front and back yards:

Cook on the grill and eat meals? ☐ Yes ☐ No _____

Help young family members on play equipment? ☐ Yes ☐ No _____

Play with/care for a pet? ☐ Yes ☐ No _____

Relax in a pool/hot tub? ☐ Yes ☐ No _____

Yard maintenance/gardening? ☐ Yes ☐ No _____

Wander on the property? ☐ Yes ☐ No _____

Birdwatching? ☐ Yes ☐ No _____

Socialize with neighbors? ☐ Yes ☐ No _____

Paint, craft, read or play games? ☐ Yes ☐ No _____

Woodworking projects? ☐ Yes ☐ No _____

ADDITIONAL INFO TO CONSIDER:

GARAGE

Access to the garage from inside the house ☐ Yes ☐ No Width of doorway? _____ Height of thresholds? _____

Ability to safely reach door locks/light switches? ☐ Yes ☐ No Need ability to raise wheelchair to safely reach these? ☐ Yes ☐ No

Height of the garage opener _____ Need ability to raise wheelchair to safely reach? ☐ Yes ☐ No

Can location of opener be moved? ☐ Yes ☐ No

Stairs present? ☐ Yes ☐ No How many? _____ ☐ Planning to use a temporary ramp OR ☐ Planning to build a permanent ramp

Ramp incline and length (rise and run)? _____ ☐ Straight ramp OR ☐ Ramp with turns # of turns _____

☐ Ramp has gradual turns ☐ Ramp has tight 90-degree angles Turning radius/clearance? _____

☐ Garage floor flat OR ☐ Garage floor slightly angled

☐ Garage floor surface smooth OR ☐ Garage floor surface cracked

Is there enough clearance around the car to maneuver wheelchair? ☐ Yes ☐ No

Wheelchair has clearance to enter accessible van while in the garage ☐ Yes ☐ No

Transferring in and out of the van has to take place outside in the driveway or street ☐ Yes ☐ No

Location and measurements of floor space where wheelchair can be stored when not in use: _____

COMMUNITY ACTIVITIES

List destinations outside the home that you frequently visit:

☐ Work/Office Building

☐ Doctor's Office/Hospital

☐ Grocery/Drug Store

☐ Barber/Hair Salon

☐ Department Stores

☐ Schools/College Campus

☐ Library

☐ Movie Theater

☐ Restaurants

☐ Aquatic Centers

☐ Adaptive Sports

☐ Family member and
friends' homes

☐ Travel for Clinical Trials/Vacations

☐ Planes, Trains, Automobiles
and Boats

☐ Amusement Parks

☐ Spectator Sports and Arenas

☐ Gyms and Fitness Centers

☐ Hobbies

☐ Rough Terrain Activities
(Hiking, Fishing, Hunting,
Snow Activities and Beach
Activities)

For each location and activity, spend time documenting the mobility requirements needed to access them and safely/successfully participate in them. This includes things like:

- *Travel time and distance needed to get to a destination in a wheelchair (this may determine the battery size your chair should have)*
- *Street crossing signal durations and wheelchair speeds required to safely cross streets in a timely manner (you may decide to request a particular wheelchair based on it's maximum speed capabilities)*
- *Sidewalk widths, curb heights, doorway widths and threshold heights (sidewalk and doorway widths may determine the size of the wheelchair frame you need, and curb and threshold heights might persuade you to choose a wheelchair with better curb climbing capabilities or the ability to climb steeper inclines)*
- *Various door types and level of accessibility (manual swing doors vs. manual revolving doors vs. automatic sliding or opening doors)*
- *Stairs, ramps, elevators and escalators*
- *Wheelchair features or accessories required to access certain destinations or participate in certain activities (such as a chair that can raise up in height to sit at a bar for happy hour with co-workers or friends)*

For each recreational activity that is for entertainment or pleasure, be prepared to explain why those activities are important to you, how often you participate in them, and how they improve your physical and mental health and overall quality of life.

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