

FSHD & Orthotic Technology: *Understanding Bracing and What May Be Right For You*

Presented by

allard USA

FSHD Connect 2020

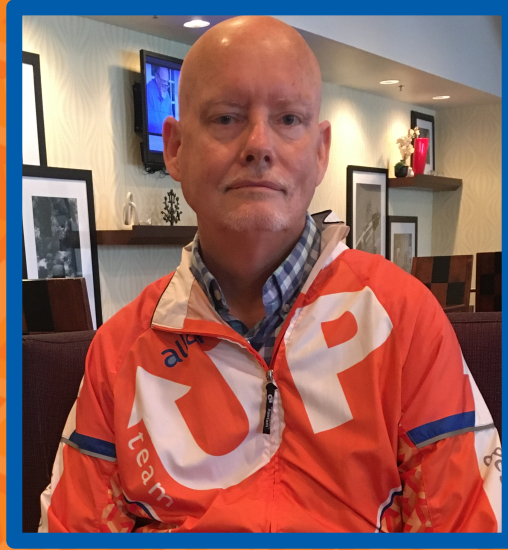
June 27, 2020

team **UP**

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Meet Rod Fulmer



Crash Course:
*Understanding the
Terminology*

Braces are referred to as **Orthoses** (or- THO- sees), singular is **Orthosis**

- From Greek word “**ortho**”, which means “to straighten or correct”

Field of Orthotics = the fitting of Braces or Splints which help to control/guide/support weakened or under-functioning body parts

Artificial limbs or body parts are called **Prostheses** (praas-THEE-seez), singular is **Prosthesis** (praas-THEE-sis)

- From Greek word “**prostithenai**” meaning “to add to, an addition to”

Field of Prosthetics = the fitting of Artificial Body Parts which are designed to replace missing or deformed anatomy

- Practitioners in these fields are called **Orthotists and Prosthetists**
- Their clinics are called “**O&P**” or “**P&O**” facilities
- This healthcare field is referred to as **the O&P industry**

“Minding your P’s and O’s”

- Orthotists and Prosthetists are *NOT medical doctors (MDs)* but instead *are medical clinicians* with:
 - At least a Masters Degree in O&P
 - 1-year residency before becoming a certified practitioner
 - Passing of Certification Exam
- O&P involves *restoring function of biomechanical actions* (such as walking, grasping, balancing, etc.)



Orthotics refers to the fitting of braces or splints *onto existing body parts*

Prosthetics refers to the fitting of devices *where body parts are missing*

Non-Orthotists Who May Assist with Orthotic Needs

Podiatrists: Doctors Of Podiatry Medicine (DPM), different than MDs, treat lower extremities only.

Orthopedists/Orthopedic Surgeons: MDs specializing in treating issues of the skeletal and muscular system including muscles, joints, bones, cartilage, ligaments, and tendons.

Pain Management & Rehabilitation (PM&R) Docs: also known as ***Physiatrists***, are MDs who treat a wide variety of medical conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons.

*For chronic or progressive conditions it is best to see a **certified Orthotist** for your orthosis needs!*

Orthotic Interventions and FSHD

- Scapular Winging
- Shoulder Weakness

Very few functional orthoses, would be custom-designed

- Abdominal or Spinal Weakness
- Joint Weakness

OTC back braces for lumbar support for better spinal alignment, Knee braces may help stabilize positioning

- Hamstring/Quadriceps Weakness

Knee-Ankle-Foot orthoses (KAFOs) may help with postural alignment and stabilization

- Foot and Ankle Weakness/Foot Drop:

✓ *Foot Orthoses (FOs) for optimal alignment*

✓ ***Ankle-Foot Orthoses (AFOs) for multiple advantages:***

- | | |
|---------------------------|------------------------------------|
| ❖ Preventing falls | ❖ Improving Gait |
| ❖ Delaying muscle atrophy | ❖ Improving balance |
| ❖ Reducing fatigue | ❖ Promoting higher activity levels |



The “ABCs” of AFOs

- *An Ankle Foot Orthosis is a brace that restores as close to normal gait as possible, whether just for walking or for higher levels of activity like hiking, running or cycling*
- **Common Materials used in AFOs:**
 - ❖ Plastics
 - ❖ Metals
 - ❖ Carbon Fiber
 - ❖ Kevlar®
 - ❖ Leather
 - ❖ Combinations of all
- **Options in AFOs:**
 - ❖ Custom-molded to fit
 - ❖ Straight Off-the-shelf/Prefabricated
 - ❖ Customizable PreFab Shell



Staggering Number of AFO Styles - No Universal Terminology for AFOs

Static - usually solid, semi-rigid plastic AFOs
(immobilizes the foot and ankle in neutral position)

Dynamic with articulating joints (immobilizes the foot but allows some flexion and extension of the ankle)

Static - Dynamic carbon/composite
(functions similar to plastic AFOs but often lighter weight, more ROM)

Dynamic Response, Floor-Reaction carbon composite AFOs
(includes ground-reaction assist benefits)





Benefits of AFOs – For Lower Extremity Deficits

*“Less tripping=less falls=less concussions=less hospital visits=happy Carden and a less worried family. Being able to walk further for longer. Walking up stairs is easier. My gait is more fluid. Less overcompensation. Tiring less frequently throughout the day. Better stability. **Warning: Happiness from being able to walk further and more fluently may be contagious. Proceed at your own risk.” - Carden Wyckoff***

From **AFO's are like buying jeans**
Strongly.MDA.org, 1/31/2014


- Preventing & correcting of damage/deformities caused by inefficient gait
- Reducing pain from uneven weight-bearing forces
- Assisting balance & supporting better posture
- Reducing the chance of tripping & falling
- Restoring proper gait mechanics
- Reducing fatigue & energy cost of walking with neuromuscular issues
- Reducing rate of muscle atrophy
- Promoting higher level of activity & duration of activities without easily tiring

Who is a candidate for bracing? Am I ready for an AFO?

Uncorrected gait and balance issues can lead to progression of further joint issues, muscle weakness and fatigue, increased risk for falls, and overall negative impact on quality of daily activities!

Questions to ask yourself:

- Are you stable walking or do you trip/fall often?
- Are you comfortable walking on uneven terrain?
- Do you have difficulty balancing?
- Can you manage stairs easily?
- Do you have difficulty standing for long periods of time?
- Do you experience persistent lower back, leg or foot pain?
- Can you walk considerable distances without significant fatigue, pain or other gait issues?
- Do you avoid certain activities/events due to mobility issues or fear of falling?
- Have mobility challenges affected your ability to succeed or move up in the workplace?
- Have mobility challenges affected things you participate in with your family?
- Does your family worry for your safety when walking/traveling independently?
- Are you interested in maintaining as much mobility as possible for as long as possible?
- Have you considered how wheelchair/scooter may bring additional burden? (financial & health challenges, life-expectancy shortened, physical barriers and obstacles, etc.)



**This info and
more available
upon request**

About ALLARD

- In 1997 Allard released first ToeOFF® , recognized as a *quantum leap in AFO technology*
- More experience than any company in the industry—over 20 years—*makes Allard the world leader in carbon composite AFO technology*
- Dedicated development team continually and aggressively researches new technology and designs to continue to make *“Support For Better Life”* a priority
- Offers generous *Warranty* and a *30-day Patient Satisfaction Guarantee*
- Committed to *Support For Better Life*, with a portion of sales of each brace going towards grants for *Dralla Foundation*, a non-profit providing *Unforgettable Days* to people living with mobility issues
- Leads the industry in Community Outreach: *GetBackUpToday.com*, *TeamUP Movement*

Free
Brochure
Available

Support for Better Life!

AllardAFO.com



AllardUSA.com



Dralla.org



GetBackUpToday.com



About ALLARD AFOs

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ANTERIOR DESIGN Extends up from footplate onto front of leg to avoid pressure on the calf & Achilles.

LATERAL STRUT is on the outer side of the footplate to create stability and function.

COMFORTABLE The shin plate provides for a more comfortable design for the user.

THIN The extreme thinness of the product makes it light and almost invisible under slacks or trousers.

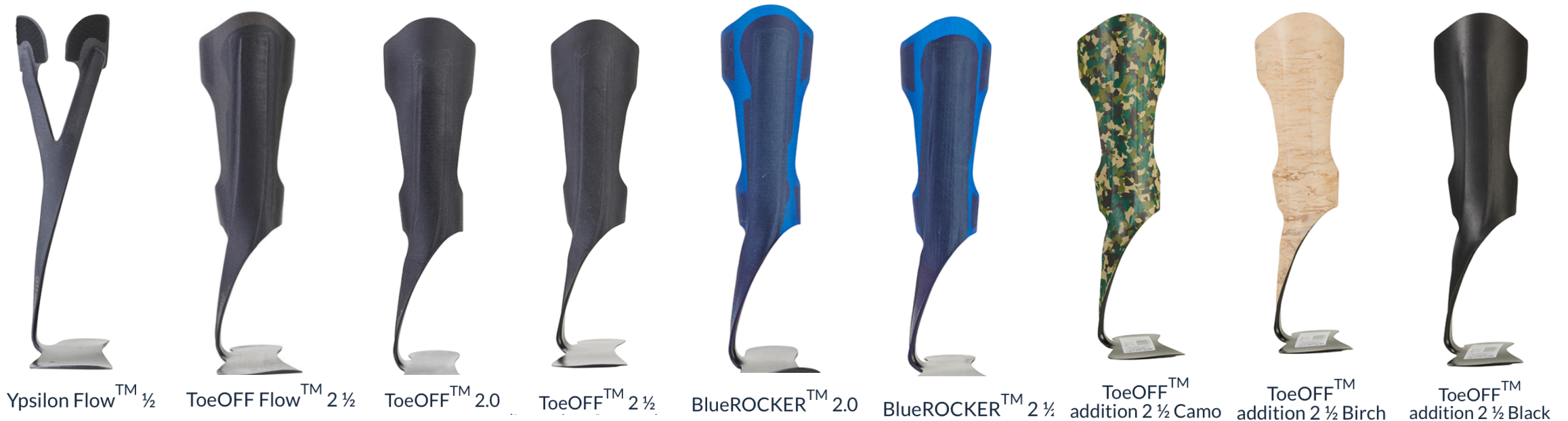
DYNAMIC FOOTPLATE Unique layup and shape contributes to a more dynamic, functional, and fluid gait pattern.

FITS IN SHOE The thinness of the footplate often avoids the need to increase the shoe size.

GRADED STABILITY To accommodate different needs, sizes & products are graded in stability & dynamic response.

LIGHTWEIGHT Made of Carbon fiber, Fiberglass and Kevlar they are extremely lightweight yet structurally superior.

OPEN HEEL Allows greater range of motion to achieve more normal gait, eliminates pressure on Achilles, calf & heel



ALLARD AFOs: *CUSTOMIZED to YOU*

✓ Multiple Models and Sizes Available

✓ Allard Accessories

- Multiple Liner/Interface options
- Multiple Strapping Options
- Orthotic Inserts
- Padding, MIKROFIX™ kits & Wedges

✓ Orthotist customizations:

- Trimming of footplate/shell
- Lateral/medial posting of brace
- Custom orthotic inserts
- Metatarsal pads
- Ankle stabilization



Minimal Weakness? You'll Want More Flexible AFO

Significant Weakness? You'll Want More Support

How do I know what's right for me?

There is no **ONE** brace that is right for **EVERYONE**

Choosing best brace for **YOU** needs to be a partnership with your Orthotist

Advice from long-time brace wearers (from lessons learned the hard way!):

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and more
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- Look for the **least restrictive brace** that still addresses **your specific needs**
 - to ensure the most muscle/joint activity & range of motion for high functionality
 - to discourage muscle/nerve atrophy by utilizing more of your own power
- Look for braces that are the **MOST comfortable** and **MOST functional for YOU**
 - you're not likely to wear a brace that isn't comfortable
 - you want a brace that performs well for the activities most important *to you*
 - if a brace is "uncomfortable" at first, it may lead to more serious issues after long-term use
- **If possible, TRY before you BUY:** ask about manufacturers that allow a trial or testing option
 - with insurance coverage often a challenge, you don't want to get stuck with the wrong brace
 - **you may have to wait 5 years** for insurance to approve coverage of a different AFO!
 - inquire about **Warranty options** and understand the **fine print**

How do I get an AFO?

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- You'll need a ***Doctor's Prescription*** – Obtain this from a medical doctor. If you want to try an Allard AFO the prescription must say “Allard AFO – No substitutions”, otherwise the orthotist can give you other versions that may not be of the same high quality, have same trial period & warranty offers. This doesn't mean you have to then order an Allard brace but it allows you the opportunity to try it to see if it's the right fit for you
- ***Check with your insurance company*** to know whether they cover the whole/partial cost of your brace
- ***Make appointment*** with certified orthotist:
 - Ask if they accept your insurance
 - Ask if they have experience fitting someone with FSHD & any other conditions you may have
 - Ask if you will be able to try different types of AFOs – both plastic and carbon fiber – know what your options will be
 - Understand that you will need to work with an orthotist who is willing to work with you—it's going to be an ongoing partnership so you need to feel comfortable with your communication
 - ***Research beforehand*** which AFO options are available, ask the Orthotist which brace manufacturers offer a “***trial period***” or a way to test different AFOs before you buy
 - Ask about all ***warranty options*** available
 - Ask what customizations can be done to the various AFO options; remember, ***CUSTOM doesn't mean BETTER but “CUSTOMIZABLE” is important***

How do I get an AFO?

Your First Appointment

- Take your prescription
- Prepare list of what you are hoping an AFO will do for you—make sure you explain what activities are important to you
- Wear the shoes you wear most often, as well as other frequently worn shoes. The shoe is an integral component of how the orthosis fits and functions so it is important the orthosis be designed to accommodate your shoes
- Bring any walking aids you currently use
- If you have previously worn an AFO and still have it, take it
- May need additional bracing to address hyperextension/muscle weaknesses in knee/leg
- Orthotist should perform a thorough and relevant evaluation, discuss AFO options with you, discuss pricing and payment options
- ***Ask about insurance regulations in your state; you may not be eligible for a different brace for up to 5 years.***

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Rod Fulmer's Top 5!!



“Please let me know if you have questions, I am eager to assist if sharing my experience may be of use to you.” -Rod

1. Deciding upon an AFO is a personal decision that should be made in partnership with your orthotist. Just *don't feel pressured into a brace that you aren't happy with* – speak up, do your research and be your own best advocate
2. *“Custom” doesn't always mean “Better”* when it comes to AFOs; hard plastic, custom-molded plastic braces are no fun and not nearly as functional as “Customizable” options
3. *It's important to remain as active—and ambulatory—as possible* for as long as possible, our lives depend on it because studies show that life expectancy can go down once you become wheelchair dependent. Wheelchairs can mean dealing with psychological adjustments and new obstacles and barriers
4. Getting the best AFO for YOU may be costly without full insurance reimbursement, but *think about the personal costs to you/your life if you don't invest in useful technology* that will prolong quality of life
5. If you have problems getting a brace that you're happy with—whether it's due to lack of access, financial hardship or other barrier—do not give up. Get creative, see what resources may be available to you that you may never have considered—just *don't give up without a fight*

What are the challenges of AFOs?

Anything new usually comes with a learning curve

- AFOs can limit range of motion and this may take time to get used to.
- Driving a vehicle may require some adjustments, but there are many ways to make driving possible/practical for all
- Walking down stairs and downhill will be different and may take time to feel confident
- Finding the right shoes for you AFO may be a challenge, inquire at GetBackUPToday.com for great options

What are some of the issues you should immediately bring to the attention of your provider?

- You continue to trip/fall
- You feel any pain or discomfort from the orthosis or pressure from your shoes
- You can't walk as far as you can without the AFO
- You feel any pain discomfort in your knees, hip, or back that you don't feel when not wearing the AFO
- If you are wearing an Allard AFO, you start to feel you do not receive as much "push-off" assist as you initially did

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What if my orthotist doesn't have experience fitting Allard AFOs, or I'm not happy with our "partnership"?

- You can switch to another provider at any time! Visit www.bocusa.org or www.abcop.org to find certified O&P providers in your area. If you are considering an Allard AFO to meet your needs, email info@allardusa.com or call 888-678-6548 and ask for the contact information for your Allard District Manager.
- **Know your options! You also don't have to go with the first brace your provider recommends—do your research before going home with a permanent (or 5-year) brace!**



Thank you for Joining the Movement by putting yourself on the map. You're now a part of a supportive, encouraging group who inspire each other to overcome challenges and Get Back Up. If you haven't already, please take time to read about TeamUP, and individual inspiring stories on the website. Please share our site with others and consider sharing your own Inspiring Story by e-mailing us at inspired@allardusa.com

facebook.com/getbackuptoday

twitter.com/GetBackUpToday

GetBackUpToday.com



Join the TeamUP Community!

By uniting as a team, we can shine a light on Foot Drop and the conditions that lead to it. Here's why you should join our movement:

- Get unique Get Back UP Today goodies to show off your support
- Share your story with thousands of members and connect with new friends
- Receive monthly updates, inspiring stories and helpful tips

www.getbackuptoday.com



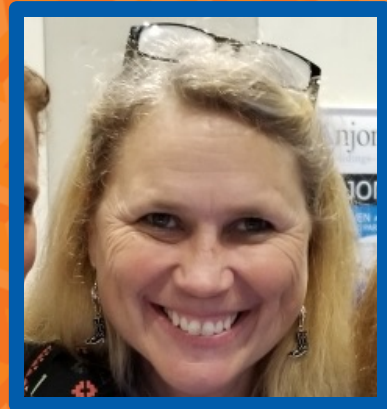
***Please stick around for our Question & Answer Session immediately after this presentation.
We will provide links to downloadable documents so that you can access all information provided here today!***



Additional Resources

www.getbackuptoday.com

www.allardusa.com



Post-event, direct all questions to: **beth.deloria@allardusa.com**

Thank you for your participation!