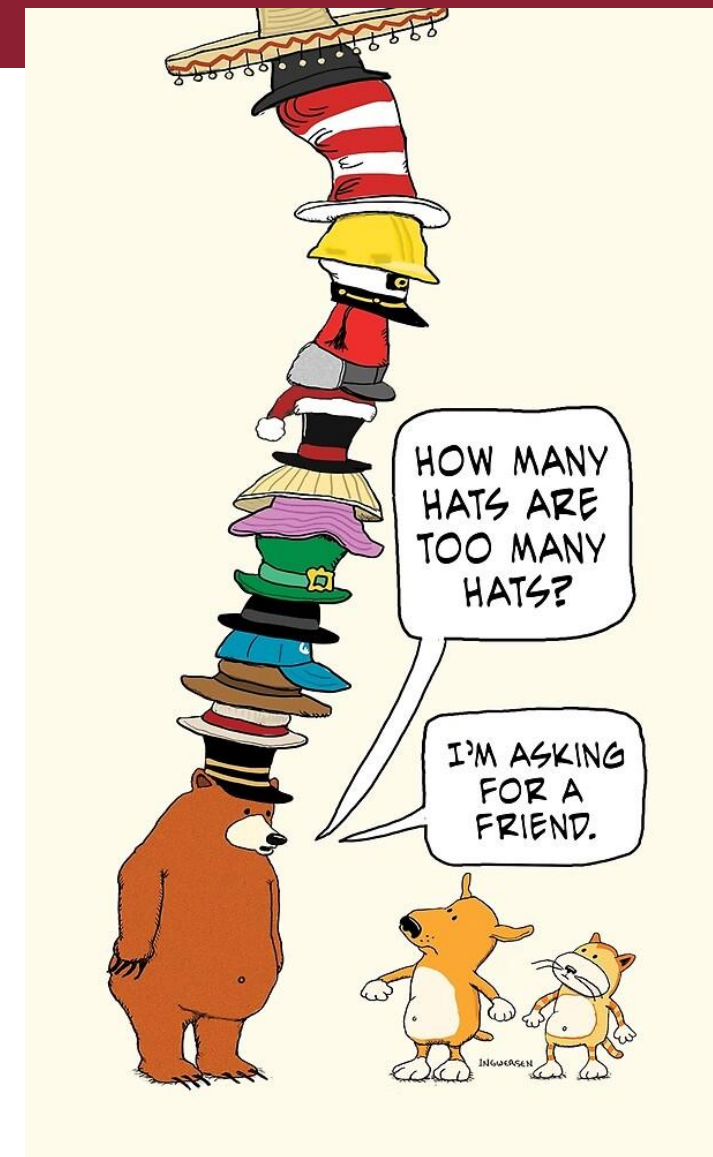




Chapter Leaders

The Hats Your Wear!

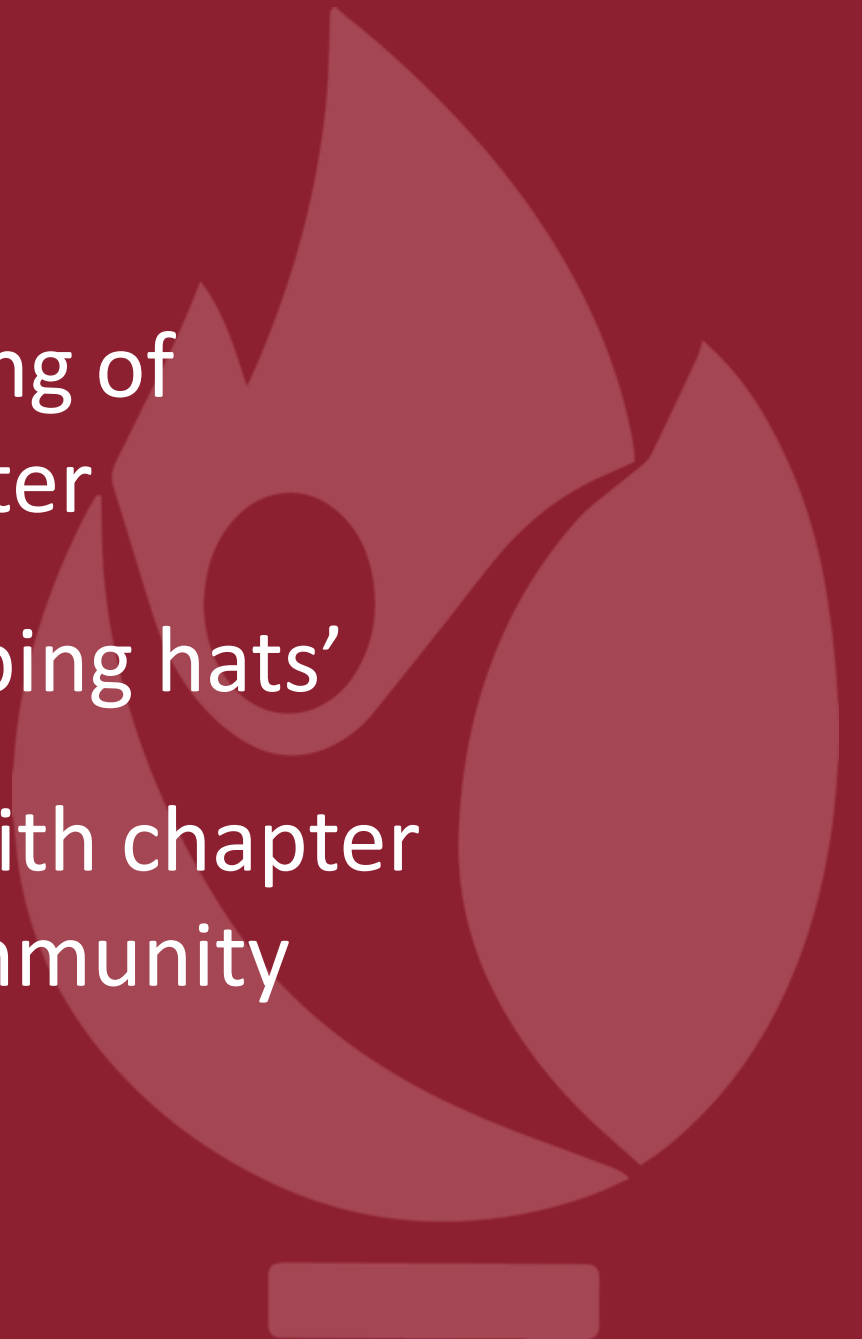


What you can expect

Leave with a greater understanding of various aspects of leading a chapter

Be more comfortable with 'swapping hats'

Feel more at ease in discussion with chapter members, patients, and local community connections



Rules of Engagement

We want to hear from you –
Jump on in!

Keep us honest - Call us on it when we fall short!

You're in control - Use your mute button if need be

Respect the 'Parking Lot'



As a Chapter Leader, you wear many hats..

- FSHD Society Onramp
- Community Connector
- Resource Builder
- Family Advocate



FSHD Society Onramp

- Provide a local connection
- Help newcomers navigate their way
- Offer helpful resources, guide people to what they need/could help
- Make the many things we do/offer more accessible



Community Connector

- Help people find each other: in-person, online, and one-on-one. And have FUN!
- Connect families to local resources
- Represent the FSHD Society locally
- Build relationships with the CTRN, clinicians, support resources
- Represent the FSHD Society online



Resource Builder

- Ask chapter members who/what they like/need
- Make note of local resources – Google Doc works!
- Make note of special interests and skills of members (we can add to their SF record; share back a full list later!)
- Leverage relationships for sponsors, team captains, and other forms of financial support



Family Advocate

- Listen well
- Act as a liaison between your local community and national staff
- Share concerns and ideas with us
- Share with each other – collaborate!



Stay **Connected**, Informed, *In The Know!*

- Volunteer Resources Page:
www.FSHDSociety.org/Volunteer-Resources
- Volunteer Leaders Facebook Page:
<https://www.facebook.com/groups/2184658054918993>
- Volunteer Leaders on Microsoft Teams:
https://teams.microsoft.com/l/team/19%3aXAw7D7hiR2ml6P_rs3V4rF56lsfWGt4qTh3zFiH4CA1%40thread.tacv2/conversations?groupId=053bc1bc-5035-4f19-b284-2ac17ffd0622&tenantId=3fcab860-edd0-4e50-8f41-9f4ce87abcab
- Cruise around FSHDSociety.org on the regular

Stay **Connected**, Informed, *In The Know!*

- USE YOUR OFFICIAL EMAIL @fshdsociety.org
- Read the monthly Hot Sheets
- Read and refer to the quarterly *In The Know* doc
- Join Jack for a volunteer-only discussion each month on Zoom, first Monday, pick either time that works for you
- Check in often with your regional director



THANK YOU!

