

# How can I be proactive about my health care?

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# FDF Resources: A Place to Start

Founded by patients to help improve patient's lives

## **Advocacy:**

Paying attention to the public policy that affects FD/MAS patients.

## **Research:**

Advancing the science of FD/MAS to find a cure or treatment.

## **Education:**

Supporting doctors and patients to get the care that they need.

# What does education have to do with progress?

The more you know...



the more likely you are to get what you need.

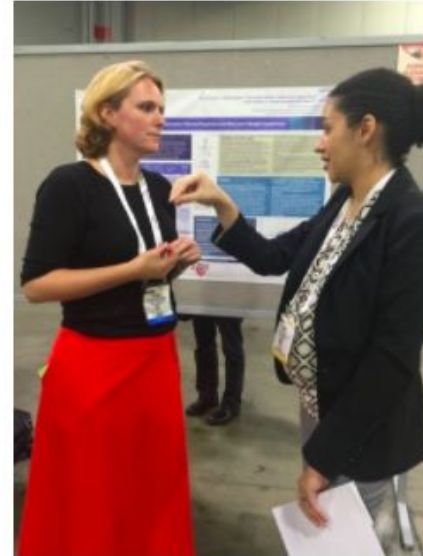
# Web Resources

- Recommended Treatment Guidelines
  - Print this for yourself as a guide
- FAQ page
  - Answers in brief
- Video/Podcast Library
  - Hear it from the experts.



# More Web Resources!

- Library of Published Research
  - The source material
  - Print this and bring this to your doctor
- Newsletters
  - We share the latest news
  - We highlight other patient stories
  - We ask for your input



**Clinical Researcher Natasha Appelman-Dijkstra from the Netherlands speaks with Deanna Portero, Executive Director of the FDF**

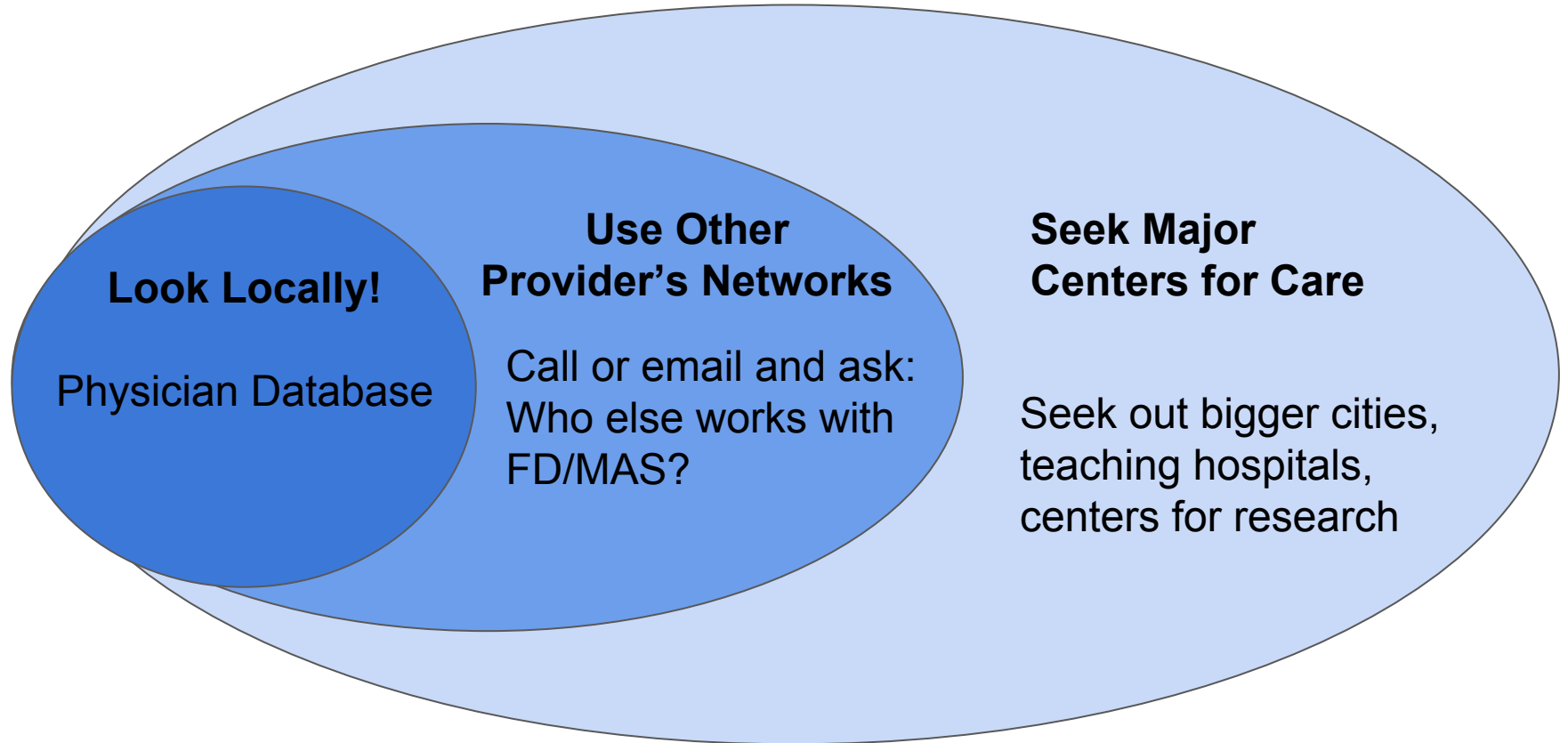
# Finding a Physician

## Physician Database

- Reviewed by MAC
- Geolocate
- Search by specialty
- Always looking to add more!



# Finding a Physician



# Working with Insurance

## Understand your coverage

- Try to find providers that accept your insurance
- Understand your benefits.
- Ask when you don't understand.

## Appeal for the changes you need

- Write and explain your needs
- Share your story.
- Document everything

**Be firm, polite, persistent**





# Reach Out

- Get Involved
  - The more you know
  - Patients can and should drive progress!
- Connect with us!
  - Find us and the private patient group on Facebook
  - **WE** are here to help.
  - [info@fibrousdysplasia.org](mailto:info@fibrousdysplasia.org)

