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
Finding a Physician

Physician Database

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

Look Locally!
Physician Database

Use Other Provider’s Networks
Call or email and ask: Who else works with FD/MAS?

Seek Major Centers for Care
Seek out bigger cities, teaching hospitals, centers for research
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