Dupuytren Research Group Dupuytrens.org

#### Who We Are

Dupuytren Research Group is a 501(c)(3) nonprofit charity: doctors, patients, and Dupuytren disease advocates working together to cure Dupuytren disease and related conditions. *We are the only global organization focused entirely on this goal.* 

> We Have One Goal Cure Dupuytren Disease

# What We Do

- **1. Education** to increase awareness of Dupuytren disease and the need for better treatment options.
- 2. Fundraising to support new research needed to find a cure for Dupuytren disease.
- 3. Research to find the cause and develop better treatment a cure.

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DUPUYTREN DISEASE AND DUPUYTREN CONTRACTURE



DUPUYTREN RESEARCH GROUP Your Hands Are Your Life.

## **Dupuytrens.org**

# **Our History, Our Vision**

Dupuytren Research Group began as the **Dupuytren Foundation. DRG is a 501(c)(3)** nonprofit charity working for a future without Dupuytren disease.

We host conferences, publish textbooks, educate patients, and conduct Dupuvtren research. We sponsored the 2010 and 2015 International **Symposia** on **Dupuytren Disease. Textbooks from these** are the leading Dupuytren publications of this decade.

We believe the best Dupuytren advocacy is *finding a cure*. Our goal is to eliminate the need for Dupuvtren procedures. A blood test for Dupuvtren disease is the single most important step in research for a cure.

Because Dupuytren disease is different in each person, we need large scale research. We created the International Dupuytren Data Bank to develop a Dupuytren blood test. This research project uses online crowdsourcing to collect data and blood samples for genetic and other biomarker tests.

With a team of top scientists spanning the globe, we are the forefront of research to find the cause and the cure of Dupuytren disease.

#### What *Is* Dupuytren Disease?

Dupuytren disease affects the palms and fingers. It causes Dupuytren contracture, which makes fingers permanently bent. It is named for French surgeon Guillaume Dupuytren (pronounced "DOOP-a-tren").

Early signs are nodules (lumps) or cords (tightness) in the fingers or the palms. *Contractures* occur later, often over years.

Over 10 million Americans have some of these signs. 3 million have bent fingers from Dupuytren contracture. Those with severe disease risk being crippled despite all available treatment.

Dupuytren disease is common in seniors. Men develop signs earlier than women. Half of those with signs of disease will have contracture during their lifetimes.

The cause is not yet known. It's genetic but can skip generations. It may be aggravated by injury or by heavy manual labor. Most often, it begins for no clear reason.



Dupuytren contracture in identical twins

# How Is It Treated?

The most common treatments are open surgery (fasciectomy) and minimally invasive procedures such as collagenase enzyme injection and needle fasciotomy.

Procedures are only for bent fingers or if the palm can't fit flat on a table top. Best results are for bends of 40 degrees or less.

Open Surgery

Treatment before fingers bend, using radiation or cortisone shots, is still controversial.

There is no cure - yet. Most people do well after treatment, but often need

Minimally

Invasive repeat procedures. Open surgery lasts the longest, but recovery can also be long. Minimally invasive treatments have less risk and shorter recovery, but don't last as long before contractures return. If contractures do return, these procedures can be repeated, but can be more risky and less effective.

The Dupuytren Research Group goal is new treatment to prevent contracture and prevent recurrence after procedures.