



DRG Newsletter

DUPUYTREN
RESEARCH GROUP
Your Hands Are Your Life.

2020 | Issue 1

A Fresh Start

Along with the rest of the world, the Dupuytren Research Group is adapting to changes imposed by COVID-19. We are working from home other than short trips for the postal mail. We are using Zoom to conference with DRG leadership, collaborators, and the global Dupuytren community.

We're moving forward with our core research project, the International Dupuytren Data Bank (IDDB). We are updating our Dupuytren Blood Biomarker Pilot Study logistics to accommodate COVID-19-related changes.

A new IDDB questionnaire is about to go out! IDDB enrollees can update their progress and answer further questions to give more clues to the biology and behavior of Dupuytren. *Watch for it!*

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The IDDB is the largest patient-reported database of Dupuytren disease with a more complete profile of the global Dupuytren community than prior studies. *See what we have learned so far.*

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The goal of the IDDB is new data and resources to match treatment to each person's *individual biology* and develop new treatments to *prevent contractures*. *Learn what is happening now and our plans for the future.*

IDDB Progress

The International Dupuytren Data Bank launched in late 2015 and is now in its fifth year with 4465 enrollees in 48 countries. Ninety-five percent of enrollees have Dupuytren. The remainder are control participants without Dupuytren.



The dark blue areas in this map are countries where IDDB participants reside.

The goals of International Dupuytren Data Bank research

- Develop a detailed picture of every stage of Dupuytren. Almost all we know about Dupuytren is *after* people have bent fingers, which is too late. We need lab data on *early* Dupuytren to test treatments that can *prevent* contractures.
- Develop a blood test of *Dupuytren activity*. We need this to develop new preventive treatments and to test them in months, not years. We will need blood tests on hundreds of people with and without Dupuytren to do this.
- Create a saliva DNA test of *Dupuytren risk*. To do this, we will need DNA analysis on at least 10,000 people with Dupuytren and a similar number without Dupuytren disease or related disorders.

“We need lab data on *early* Dupuytren to test treatments that can *prevent* contractures.”

Who is in the IDDB? The stats.

There are slightly more women than men enrolled. Age ranges from 20 and 100 years old. The youngest onset was age 6 and the oldest 98. *One in fourteen were younger than 30 when the first signs of Dupuytren appeared.*

Two-thirds of enrollees have at least one bent finger. One-third have had at least one finger-straightening procedure. *One in five had a corrective procedure within the first ten years of Dupuytren first appearing.*

Two in five have a history of Ledderhose, frozen shoulder, or Peyronie disease. Almost all have palm nodules. *Four out of five enrollees report tenderness, itching, or redness of their palm nodules.*

One-half of IDDB enrollees have a blood relative with Dupuytren. One in three has one parent with Dupuytren, one in thirty both parents affected, and one in six has at least one sibling with Dupuytren.



What happens next for him?

This 35-year-old man has some firm areas in his palm and a feeling of tightness. Is it tendinitis? Diabetic stiff hand syndrome? Tumor? Atypical Mycobacterial infection? Rheumatoid? Dupuytren? A combination of these?

If this *is* Dupuytren, will his fingers become bent? Will a preventive treatment keep his fingers straight? Will a corrective procedure last? Will his children face the same?

Individual Dupuytren biology varies. Some people never develop bent fingers. Some never have more than mild contractures. Some have only temporary improvement from corrective procedures. And for some, corrective procedures seem to make things worse.

Today, his Dupuytren diagnosis, personal biology, and the best treatment for him are just educated guesses. Lab tests of his Dupuytren *risk* and *activity* could take the uncertainty and guesswork out of his Dupuytren care.

What is next for you - and us?

- **Ongoing Dupuytren Blood Biomarker Pilot Study:** We will resume collecting blood tests when COVID-19 related social distancing restrictions permit.
 - We are sending *new invitations to participate* in this Pilot Study. Watch your inbox and check your spam folder.
 - Please *help recruit enrollees without Dupuytren* to participate as *controls*. Reach out to your friends, civic and religious group members, in-laws, and others to enroll as controls.
- **Next Pivotal Biomarker Study:** We will need at least 10,000 enrollees with Dupuytren to develop a genetic screening test. We are now almost halfway there. *Everyone you know with Dupuytren should enroll at <https://dupstudy.com/>.*
- **The IDDB follow up survey** is about to go out to all IDDB enrollees. *Don't miss this!* Log in and make sure your contact information is up to date: <https://wq.forwarddatabank.org/identity/account/login>

IDDB and the Future of Dupuytren

So far, IDDB data *confirms statistics* from smaller studies on age, family history, contracture progression, and associations with Ledderhose, frozen shoulder, and Peyronie disease. *New findings* include a high rate of nodule-related symptoms, worse long-term outcomes for those who need a corrective procedure than those who don't, and that Dupuytren does *not* always cause bent fingers, even over decades. These findings just scratch the surface of questions to explore in this unique resource. More will follow further enrollment and data from upcoming follow-up surveys.

IDDB enrollment is the key to developing lab tests of Dupuytren risk and Dupuytren activity. *A Dupuytren blood test is the critical step needed to find new treatments to prevent the need for corrective procedures.* The future of Dupuytren and progress to a Dupuytren cure depends on your support and participation in the IDDB.