

IDDB: The International Dupuytren Data Bank **Research to Cure Dupuytren Disease**

Introduction

The International Dupuytren Data Bank (IDDB) is a groundbreaking research study paving the way for better treatment of Dupuytren disease, which cripples hands, diminishes quality of life, and affects overall health of millions worldwide. Details are available at <http://Dupuytren.org/IDDB/> and online enrollment is at <http://DupStudy.com>.

The IDDB solves problems which have blocked advances in Dupuytren treatment for decades. It is the first study to prospectively compare Dupuytren clinical severity with blood biomarker discovery on a large scale. It is the first to use crowdsourcing for clinical data and biospecimen collection for surgical disease research. It will establish unique, valuable and enduring resources for other researchers, with access to clinical survey data, lab results, and banked blood samples.

The Need

Impact of Dupuytren Disease. Imagine the prospect of being *unable to use your hands normally* to wash, reach into your pocket, use a keyboard or even shake hands. Imagine this *worsening* and being told there is *nothing you can do* to stop this, that your only option is a procedure which probably won't last and *might make things worse*. Imagine passing this risk on to *your children* - and to their children. *Multiply this by millions*, and you've still only imagined *part* of Dupuytren disease. This is an inherited disease spectrum affecting one or more areas including hands, fingers (Dupuytren Contracture, Knuckle Pads), feet (Ledderhose Disease), or shoulder (Frozen Shoulder). People with Dupuytren contracture also have greater *risk for other conditions including cardiovascular disease, cancer, and early death*. In the US alone an estimated 16 million people are affected.



Recurrence despite many operations.

Dupuytren disease is one of a group of diseases which result in *fibrosis*, or scar tissue where it isn't needed. Part of the biology of Dupuytren disease overlaps that of other fibrotic conditions including cirrhosis of the liver, pulmonary fibrosis, arteriosclerosis, and some cancers. Understanding Dupuytren disease may help physicians and researchers understand these other conditions and develop better treatments for them as well.



Dupuytren contracture: trying to straighten fingers.

A new Dupuytren research model is needed.

For nearly 200 years, Dupuytren research has focused on anatomy and procedures for bent fingers, rather than on root biology. Procedures have improved, but long term results have not. Why? *Bent fingers* are the most visible problem, but they *are the effect, not the cause*. Dupuytren disease involves the entire body, not just the fingers. We must study *people*, not only their hands, to develop a prevention and cure.

The IDDB is the future of Dupuytren research. Current Dupuytren research is stuck in the past, focused on Dupuytren procedures and how long they last. We're moving beyond this, beyond procedures. Our goal is to quickly find and test medicines to *fix the cause* of Dupuytren disease and *avoid procedures*. The first step is a *blood test* to measure Dupuytren biology and quickly test medication response. Our research is the first to use proven chronic disease research tools to solve the Dupuytren challenge. We're reaching out to work directly with patients. IDDB crowdsourcing makes critical large scale Dupuytren research a reality.

The IDDB: How does it work? It's pretty simple:

1. Collect Dupuytren and other health information from people using secure online forms. The IDDB signup process starts at <http://DupStudy.com>.
2. Collect blood tests from people who have enrolled and completed follow-up surveys.
3. Analyze the blood tests to find what correlates with how bad the Dupuytren disease is (biomarkers) and what might be the wrong that could be treated (molecular targets) and use this information to develop new treatments.

Enroll today, and spread the word. The sooner we finish, the sooner we will find a cure.

The most current version of this document is at <http://Dupuytrens.org/IDDB.pdf>