2018 marks the tenth anniversary of the Dupuytren Research Group. I’m proud and excited by the progress we’ve made.

We’ve been around long enough now to have a history. We began in 2008 as the Dupuytren Foundation, the first nonprofit established to advocate for Dupuytren patients. Our first work was online content production for patient education. This expanded to sponsor conferences to help surgeons and scientists connect with the common goal of better Dupuytren treatments. The next phase was fundraising to sponsor outside Dupuytren research, which led to a critical insight: although there was very sophisticated research underway, none focused on the type of research needed to develop preventive treatments. This realization prompted a major course change: if we want this research to happen, we must do it.

All effort went into developing plans for what is now the International Dupuytren Data Bank: reaching out to collaborators, challenging the common view that Dupuytren is only a surgical problem, developing a strategy to enroll Dupuytren patients despite lack of high-volume Dupuytren treatment centers, creating a comprehensive list of potential Dupuytren blood biomarkers and the logistics to survey these, and finally, finding ways to fund this work. Forging this new path remains an exercise in persistence, shaking off false starts, impatience, and the unknown. It is working. We continue to gain momentum.

We are a small nonprofit dealing with a common complex disease which has no major research funders, no other US advocacy organizations, and no long-term outcome progress in over 50 years. We represent the growing use of biomarker research tools to improve the care of traditional "surgical diseases". Our goal is to connect patients, surgeons, scientists, and industry to forge better treatments for Dupuytren and other chronic fibrotic diseases.

Why all this effort? Simple: people with Dupuytren disease deserve better. Better recognition, better understanding, better treatment, and a better future for their families. The time is right. We have access to new game-changing research tools never used to target a Dupuytren cure.

I’m very grateful for the trust, support and hard work of everyone contributing to this effort. Together, we will change the future for all affected by Dupuytren and related disorders.

Thanks!

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Our core mission is research to transform Dupuytren care. Our research programs focus on filling in critical gaps in the understanding of Dupuytren anatomy, biology, and measurement of response to medical treatments.

Research: Pinpointing Dupuytren Blood Biomarkers
The greatest obstacle in progress to a Dupuytren cure is lack of a blood test of Dupuytren activity. Without a blood test, there is no practical way to test a preventive Dupuytren treatment. The goal of our flagship research, the International Dupuytren Data Bank, is to develop this blood test.

This study launched in late 2015 and had 3500 enrollees by the end of 2018. Candidates for our blood test pilot study will be chosen from this group. Results from this pilot study provide new insights into Dupuytren biology and open the door to large grants for further Dupuytren research.

Research: Inflammation and Dupuytren Disease
Inflammation is an important but unclear part of Dupuytren biology. The Dupuytren Research Group is partnering with researchers at the Rochester Mayo Clinic to review the evidence for the role of the molecular biology of inflammation in Dupuytren disease. This publication will be valuable reference for new research aimed at developing a Dupuytren cure.

Research: Predicting Dupuytren Progression
Researchers need better information about how fast Dupuytren progresses over time without any treatment. What happens after corrective Dupuytren procedures is well known. Little is known about predicting early Dupuytren before treatment. This data is key to see if Dupuytren is affected by medicines people take for other conditions, or how other medical conditions affect the speed of Dupuytren progression. Preliminary results from two of our studies show that before any treatment, those at high risk for recurrence have slower average contracture rates. This unexpected finding has not been previously reported and gives guidance for new research.
Research: Reexamining Dupuytren Anatomy

Three-dimensional disease anatomy models are made from CT or MRI studies. Dupuytren affects hand tissue layers in ways that don’t show up on CT or MRI, so we’ve come up with a different approach. Our work so far is a cross-sectional tour of Dupuytren tissues based on cadaver cross sections: https://youtu.be/XwyXkhHAiZ8. Virtual 3D Dupuytren models are needed to analyze Dupuytren biomechanics at different stages of disease and to 3D print a Dupuytren hand model for more realistic cell biology laboratory studies.

Research: Mapping Dupuytren Biology

Dupuytren biology involves many hundreds of molecular factors interacting in many ways. DRG research student Darien Bellido de Luna has been mapping select groups of these factors and their connections with the goal of a computer model of Dupuytren biology. This model will allow researchers to study how changes in one or more of these factors affects the entire system, and how abnormalities in the entire system might be corrected by changing just one of these factors.

Research: National Dupuytren Impact

In 2018, DRG began two new investigations on the national burden of medical care for Dupuytren and related diseases. These studies will analyze data from Medicare, Medicaid, and the VA medical system. When complete, this will be the largest investigation of its kind on Dupuytren and related diseases. It will give unique insights into the relationships of Dupuytren to other diseases and cost-impact data needed to support new federal funding resources for Dupuytren research.
EDUCATION, OUTREACH, AND SUPPORT

Public: Throughout 2018, DRG promoted Dupuytren awareness through regular features on our website, blog, Facebook, Twitter, Instagram and other social media channels. Our goal is to inform people who don’t know about Dupuytren, and to update and engage people who do.

Professional: In 2018,

- DRG physician members gave presentations on Dupuytren disease and research at academic physician conferences in the US and Europe.
- DRG supplied over 1200 patient information brochures requested by physician and therapy offices across North America.
- Dr. Eaton and Mayo Clinic hand surgeon Dr. Marco Rizzo collaborated most of the year on a new chapter on Dupuytren disease for the American Society for Surgery of the Hand textbook scheduled for publication in 2019.
- DRG hosts International Symposia on Dupuytren Disease every five years and Dr. Eaton began work with the planning committee for the 2020 Symposium to be held in Oxford, England.

Personal: Our focus is research, but our goal is helping people struggling with Dupuytren and related diseases. In 2018, Dr Eaton provided over 100 free personal consultations on request with DRG supporters by phone and in person in our West Palm Beach office.

Education: Public Outreach Seminars
DRG hosts public seminars around the country to raise awareness of Dupuytren and to discuss issues in person with Dupuytren advocates. Below, Dr. Eaton meeting with Dupuytren advocates at a 2018 Dupuytren awareness conference in Phoenix at the Arizona Capitol Museum.
Outreach: Collaboration

Dupuytren has baffled doctors for almost 200 years. When experts are stumped, progress needs ideas from experts in other specialties. We regularly reach out to experts in other fields who might have helpful ideas even if they have never heard of Dupuytren disease. 2018 was no different. For example, while in Boston, Dr. Eaton met with MIT software research PhDs Teresa Arroyo-Gallego and Ian Butterworth (left) to discuss software to measure Dupuytren effects and with National Organization of Rare Diseases president Peter Saltonstall (right) to discuss Dupuytren advocacy.

Outreach: Recognition

Dupuytren Research Group outreach initiatives include educating political representatives about the impact of Dupuytren related diseases and the need to fund Dupuytren research. In 2018, the Dupuytren Research Group was recognized by the Florida House of Representatives for Dupuytren advocacy. Here, Representative David Silvers presents Dr. Eaton with the House recognition certificate.

Outreach: Education

DRG and the International Dupuytren Society collaborate with the global Dupuytren community research to publish the leading textbooks on Dupuytren disease. Since our first textbook became available online in 2012, it has had 46978 chapter downloads and is in the top 25% most downloaded eBooks in its respective eBook Collection. This textbook had 6122 downloads in 2018. Our follow up 2017 textbook had 7893 chapter downloads during 2018.
Dupuytren Research Group was renamed Dupuytren Research Group to better reflect our mission.

Peter Geimer, Chris Giomblanco, and Laura Holmes Jost joined the Board of Directors.

The decision was made to change the organization’s fiscal year in 2019 from Jan-Dec to Jul-Jun to clarify accounting of charitable donations which peak December through January.

Our core research focus is the International Dupuytren Data Bank. Our 2018 fundraising and saving brought us to over 80% of our project’s pilot blood draw laboratory budget of $400,000. We expect to meet this goal in 2109 and begin blood testing. Results from this project will provide the preliminary data required to apply for large federal grants. Until then, our work is supported by individual donors and private family foundations.

Our fundraising expenses were in the form of outreach and direct-to-donor connections. Dupuytren Research Group does not use professional fundraising services.

2018 Administrative expenses reflect proactive steps to ensure financial transparency through a series of independent financial reviews, available on request.
PLANS FOR THE YEAR AHEAD

RESEARCH

International Dupuytren Data Bank
The blood draw phase of the IDDB pilot study will begin as soon as we reach our fundraising goal of $400,000. Once blood sampling is complete, laboratory testing will take two months to return more than 30 terabytes of raw data. For perspective, a 30-terabyte text document would be over two billion pages long. This requires cloud storage and cloud computing power, which is why we are fortunate to have been accepted as participants in the FDA’s PrecisionFDA program, which will provide these services without cost. In addition to access for our researchers, PrecisionFDA will allow us to share the anonymized raw data to vetted researchers around the world in a friendly competition. The winning team will be the one best able to identify Dupuytren patients using only gene and protein data from the blood samples. Crowdsourcing this research will be the fastest way to identify key markers of Dupuytren disease. Even with this, we expect complete data analysis to take 12 months.

Dupuytren Impact
We will continue analysis of Medicare and VA healthcare data to show the need for federal funding initiatives for Dupuytren research. This work will also look at relationships between Dupuytren and other diseases for new insights into Dupuytren biology.

Natural History of Dupuytren disease
Testing preventive treatments begins with knowledge of what happens without treatment. Our work on IDDB data and data from Dupuytren surgeons will continue through 2019. This is the first large study of its type.

Anatomy of Dupuytren progression
Our ongoing work on 3D Dupuytren anatomy will continue through 2019. One issue we’re working on is the relationship between the lengthwise shrinking of Dupuytren tissues and the angle changes that doctors measure. This will help explain why Dupuytren behaves differently in different locations and lead to more accurate ways to measure biologic activity with physical measurements.

EDUCATION, OUTREACH, AND SUPPORT
In 2019, we will continue raising public awareness about Dupuytren disease through website content, social media, print brochures and public outreach seminars. DRG physicians are scheduled to give presentations at national and international medical conferences, publish textbook chapters, journal articles, and engage physicians through personal outreach. We are nonpartisan with no political campaign activities but will continue work with congressional representatives to advocate for state and federal support of Dupuytren research.