



Dear Friends,

The Jeffrey Modell Foundation has just completed its most successful and impactful pilot program in the 33 years since we started. We recently launched a genetic sequencing program at 21 Jeffrey Modell Centers worldwide for patients diagnosed with an underlying Primary Immunodeficiency disorder. The aim of this initiative was to offer precise diagnosis and quickly provide medical professionals the opportunity for appropriate management and treatment.

Now we are proud to invite you to participate in the global rollout of this program, **“Jeffrey’s Insights”** offering **genetic sequencing to patients with a suspected Primary Immunodeficiency at no cost to you, your patients, your hospital, insurance company, or government agency!**

In our pilot program, over the past year participating patients saw a health care provider an average of 5.28 times; 42% had been admitted to the hospital, 34% to the emergency room, and 13% to the ICU. Many had multiple admissions.

158 patients were sequenced in our pilot program and at least one genetic variant was discovered in 151 patients (96%). Overall, 507 genetic variants were identified, as certain patients had multiple variants.

After genetic sequencing of 158 patients:

- 45% of responding physicians altered their suspected clinical diagnosis
- 40% of the patients had a change in disease management
- 36% of the patients had a change in treatment
- 45% of the patients had a change in outcomes
- There was an approved therapy for 80% of the patients

These results are remarkable, unprecedented, and quite simply breathtaking! This definitively speaks to your diagnostic acumen and expertise in identifying patients who are truly in need of a genetic diagnosis.

We will continue to collaborate with Invitae, one of the fastest growing genetic information companies. Invitae is a fully certified clinical diagnostic laboratory and performs full-gene sequencing and deletion-duplication analysis using next-generation sequencing technology (NGS).

This program is for those patients who you identify as having the most severe, compelling, complicated, and potentially life-threatening conditions, with an emphasis on pediatric patients. The sequencing offered will reflect Invitae’s validated NGS strategy utilizing their comprehensive Primary Immunodeficiency panel of 207 genes. JMF will provide guidance and assistance throughout the entire process of the program including information on patient eligibility, sample collection, shipping instructions, and results reporting.

- Sample collection kits provided at no cost.
- Shipping costs at no charge.
- Family variant testing will be offered without cost for any relatives of the patient who is tested and has a pathogenic variant.

- Specimen sample options include blood, saliva based, and genomic DNA testing options.
- Turn-around time is 10-21 days, 14 days on average.
- Interpretation of the identified variant(s) will be available on Invitae's online portal, without charge!

Please say "Yes" to join us! Your participation will not only benefit your patients, but will profoundly contribute to the entire Primary Immunodeficiency community. We would be appreciative if you would please email us at JQuinn@JMFWorld.org by February 15th, 2020 with one of the following responses:

YES - I would like to participate in this program!

Please send me additional information on how to get started.

NO – Unfortunately, at this time, I am unable to participate in this program.

We hope that you will agree to participate, because we know that patients without a genetic diagnosis frequently undergo a diagnostic odyssey, including numerous specialty referrals and an exhaustive number of expensive and often unhelpful tests. Delays contribute to continuing suffering by the patient with chronic infection and organ or tissue damage. Our dream is to put an end to this heart wrenching diagnostic odyssey and enhance the quality of life of patients with Primary Immunodeficiency. This is our gift to the patients!

Best regards,

Vicki and Fred Modell
Co-Founders
Jeffrey Modell Foundation



Jessica Quinn, MPH
Scientific Director
Jeffrey Modell Foundation