



# Lipodystrophy United

## Strategic Plan and Financial Disclosures





# Meet the Team

Sharon  
Halperin

Research  
Director  
and Board  
Secretary



Andra  
Stratton

Chief Advisor  
and Board  
Member



Kate  
Stratton

Executive  
Director



Francesca  
Amato

Operations  
Manager



Larry  
Seida

Chief  
Financial  
Advisory  
and Board  
President



Lori  
Seida

Community  
Support  
Liason, Head  
of the  
Newsletter  
Committee



Crystal  
Chavez

Community  
Support Liason



# Mission

**Our mission is to increase awareness and understanding of lipodystrophy among the patient community, medical professionals and stakeholders.**



## Vision



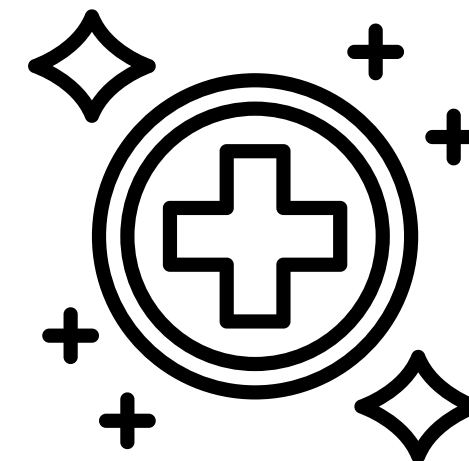
**Accurate  
Diagnoses**



**Quality  
Care**



**Effective  
Treatment**



**One day,  
a Cure**





## 2024 Achievements

In 2024, Lipodystrophy United:

- Revitalized its community.
- Advanced its mission by rebuilding its online presence, boosting social media engagement, and reconnecting patients and caregivers.
- United over 100 community members and medical professionals.
- Secured \$150,000 in fundraising—further cementing our leadership in patient education and support.

7,481

Website Visits

Since rebuilding our website in early March 2024

10,130

Social Media Views

Since February 2024

\$150K

Funds Raised

Via grants and fundraising efforts

100+

Symposium Attendees

In collaboration with the University of Michigan



### **Advocacy:**

Establish and Advance Advocacy Initiatives to Amplify the Patient/Caregiver Voice and Drive Systemic Change in Lipodystrophy Care.

### **Research:**

Advance patient-centered research that improves understanding, diagnosis, and treatment of all forms of lipodystrophy.

### **Community:**

Foster a strong, engaged, and informed community of individuals and families affected by lipodystrophy.

### **Development and Operations:**

Strengthen Lipodystrophy United's infrastructure, secure long-term funding, and expand our ability to serve the community.

## Advocacy Strategy



# Advocacy



Collaborations  
with global lipid  
and endocrine  
HCP's through  
attendance of  
ENDO and NLA



Engagement  
with national  
policy at NORD  
and Rare  
Disease Week  
on the Hill.  
Engagement  
with federal  
regulators



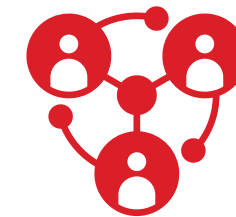
Engagement  
with the  
global  
lipodystrophy  
leaders forum

## Community Engagement Strategy



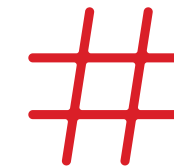
### **Tea with LU:**

Expand Tea with LU programming with open chat sessions on alternate weeks to foster community connections.



### **Consistent Engagement:**

Develop and launch a podcast featuring researchers and physicians to educate and engage the community on lipodystrophy topics. More info coming soon



### **Social Media Growth**

Implement a comprehensive social media strategy, including a content calendar and brand kit to ensure consistent, engaging communications.

## Research and Development Strategy



### **Scientific Advisory Board:**

Establishing a Scientific Advisory Board to provide expert scientific guidance and strategic direction



### **Patient Owned Data:**

In collaboration with patients, clinicians, and experienced researchers



### **Engaging the Scientific Community:**

Launch initiatives to facilitate dialogue between researchers, clinicians, and the patient community



## Operational Improvement Strategy



## Operations & Development



### **Board Development:**

Expand and strengthen the Board of Directors, establish a Scientific Advisory Board, and restructure the Patient Advisory Board for more effective governance.



### **Project Management:**

Implement project management software and clearly define roles to improve organizational efficiency and task completion.



### **Financial Strategy:**

Explore new funding opportunities, and create a comprehensive grant document to support financial sustainability.

## Total Budget - 2025

● Advocacy   ● Community   ● Research   ● Operations   ● Development

