Telehealth, Telemed, Telederm, Tele-rare:
The help you seek is virtually at your fingertips

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Hometown
Pediatric
Dermatology

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ORGANIZATIONAL OVERVIEW

- Hometown Pediatric Dermatology is a private pediatric subspecialty direct care practice primarily providing teledermatology to expand rural access to pediatric subspecialty care.
- As part of pediatric dermatologic care, rare and ultra-rare diseases are not infrequently seen.
- **We have begun to explore some of the myriad of ways that people use technology to live with their rare diseases.**

PROGRAM SPOTLIGHT

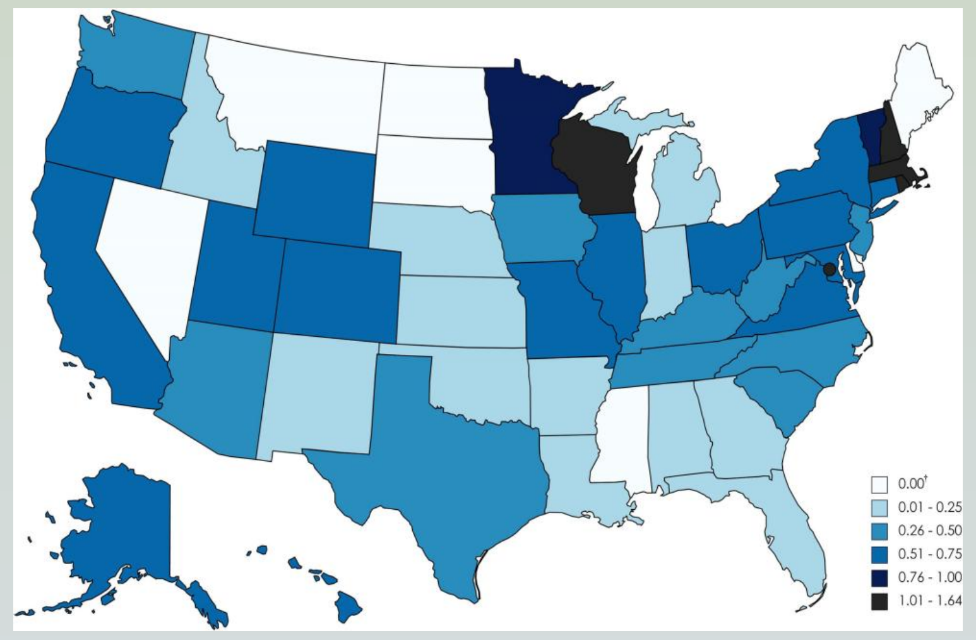
- People with rare diseases often access medical care, support, and expertise outside traditional pathways and **there are often only a few experts scattered widely about the country or world**.
- **We highlight the ecosystem of telehealth touchpoints in dermatologic rare disease communities**.
- **We note an increasing democratization of knowledge at the affected person level.**
- This serves as a more comprehensive view of the ways in which persons living with rare chronic diseases access care and support.

HIGHLIGHTS

Tele Specialty Care (physicians to patients)

- Specialists increasingly work **outside the traditional academic center/hospital-based care model;** more cash pay options; multiple states
- Can target **increasing rural access to specialty care** (specialists are concentrated in urban areas)
- Example: Hometown Pediatric Dermatology

Practicing pediatric dermatologist density



TikTok/Social Media (affected people themselves):

- Youth-run accounts post more videos on **disease education/awareness**, while parent-run accounts post more videos related to **support**
- Comment sections demonstrate **positive engagement**
- A place to spread awareness, engender a sense of community, and create a space for self-expression

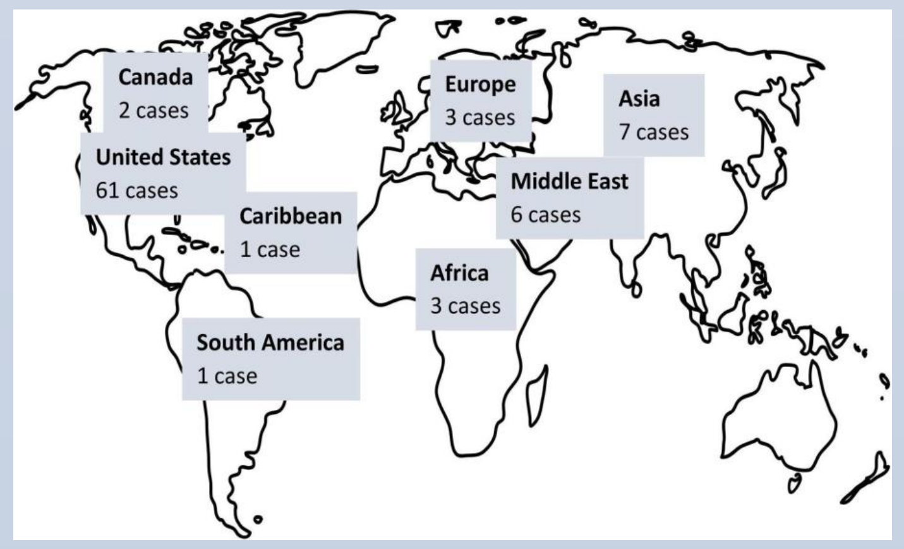
May he rest in peace.
I am 29 and have EB. Sending all my love to your little one!
Looking great girl!
You are gorgeous!
Keep fighting and stay strong!
Nice, darling.
Stay strong from one butterfly to another 🦋
You're beautiful the way you are!
Your beautiful energy is contagious!
❤️ ❤️ ❤️ ❤️ ❤️ ❤️ ❤️
I have ichthyosis too. Love to see this positivity!
Hello new friend, you are so brave.
So sorry for your loss, shes such a beautiful angel.

Other Social Media (patient groups as conduits and leaders):

- **Private patient and family support via disease-based advocacy groups** through Facebook and Instagram (DEBRA, FIRST)
- Sometimes host physician speakers

Rare Disease S&F Consultation: Teleichthyosis (clinician to clinician, NOW changing…)

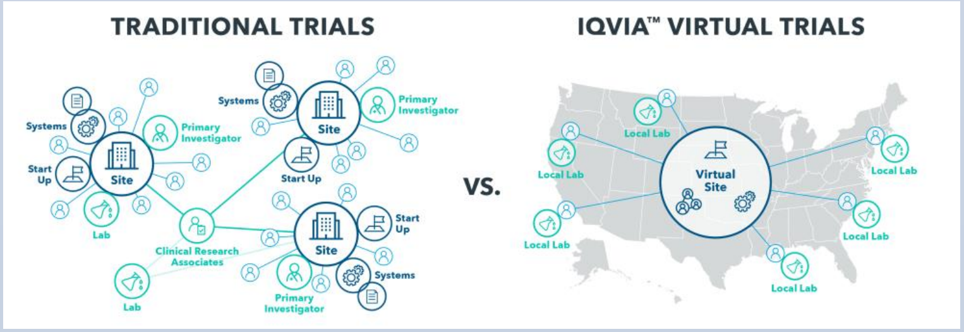
- The Foundation for Ichthyosis and Related Skin Types (FIRST) Tele-Ichthyosis program has provided consultations for people with keratinizing disorders since 2009
- Other rare disease groups have similar consultation services (PCProject, VBF)



Rare disease camps (in person experiences, used to be referred by physicians, now can self-refer)

Virtual/Decentralized Clinical Trials

- Use telemedicine, wearable devices, and home-based sample collection to conduct research outside of traditional trial sites.



FUTURE PLANS, VISION, INITIATIVES / CLOSING THOUGHTS

The current siloed self-referring model does not fit persons living with rare disease, nor their clinicians. People are looking beyond their local physicians or single specialists to find the help they need to their disease communities, social media, and broader access to care, opinions and clinical trials. Physicians increasingly look to patients for lived experience and the richness of these networks. Project ECHO for Rare Disease, but also for specific specialties. Breaking down the walls of the clinic and hospitals to fill a more complete life. AND, kids still need to go to Camp!!