

My “Ah – **HAH**” Moment...

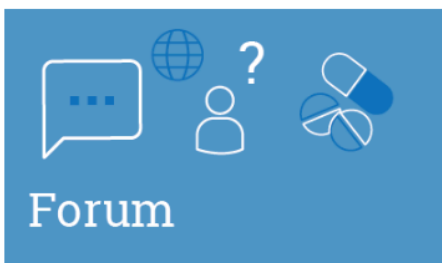
HAH : HealthCare at Home

Global Genes

University of British Columbia



We offer the Cystic Fibrosis community an active forum, blogs and medical articles, and a wealth of other resources:

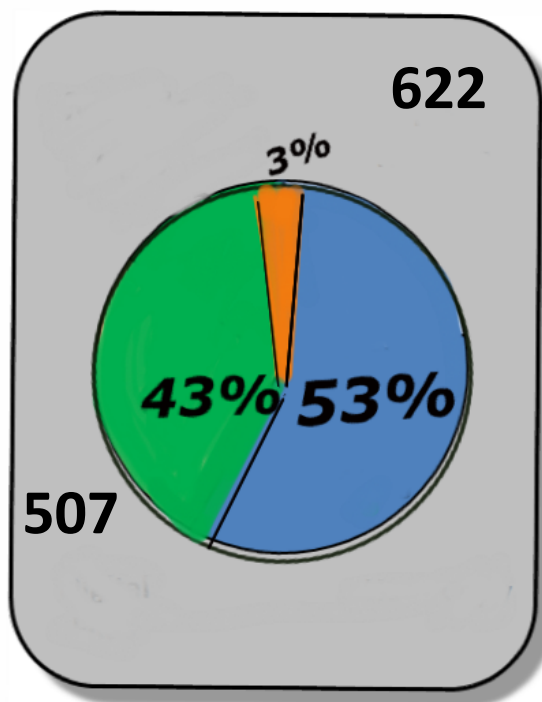


Three Things You will LEARN...

1. Meet the special community with Cystic Fibrosis
2. Unmet Need = need an APP to store and share data.
3. Learn how YOU CAN HELP

DEMOGRAPHICS

1166 PARTICIPANTS



I have cystic fibrosis 53% 622

I am a Care Giver 43% 507

None of the Above 3%

***Online survey; n= 616 adult cystic fibrosis patients. Data collected
10/17/2017-4/11/2018***

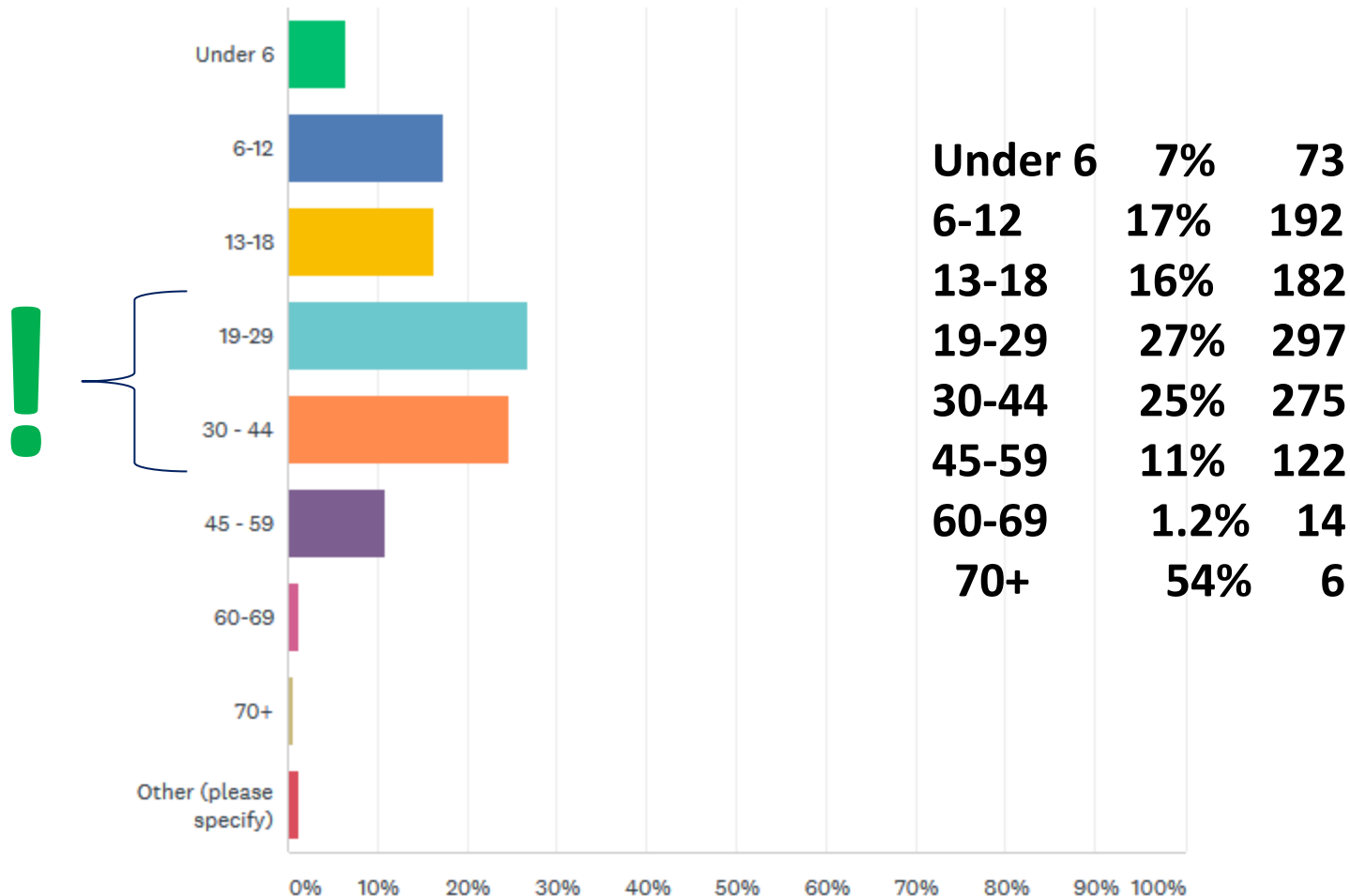
Where are they from?

20 Countries 88% USA



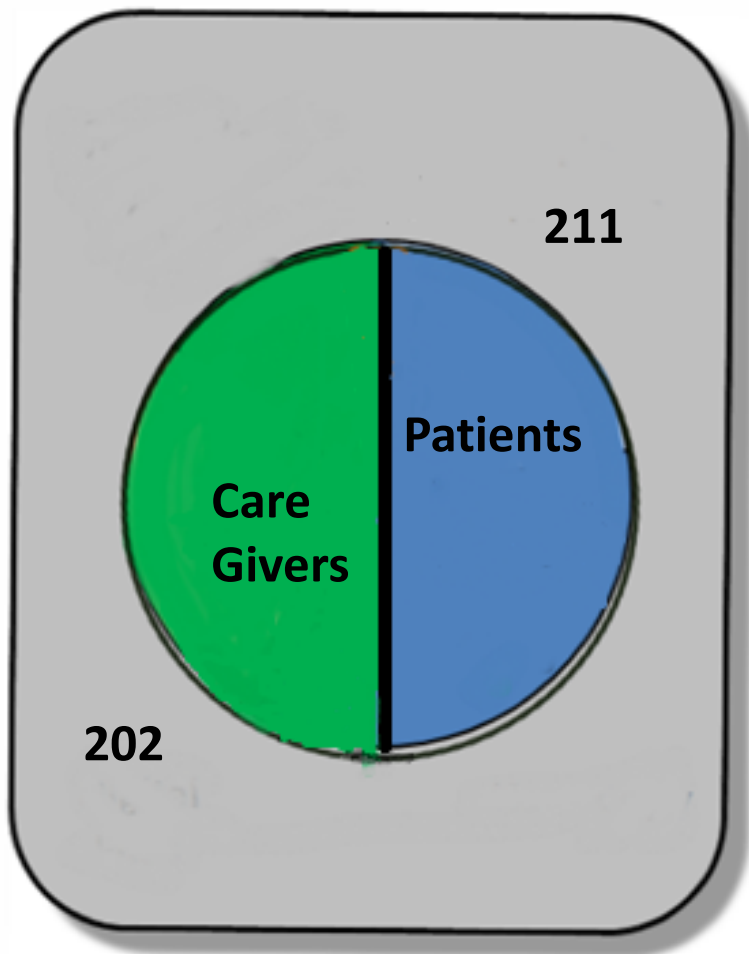
Ages

CF is no longer a “Childhood Disease”!



THE UNMET NEED

What are your CF Mutations? Optional Question



Comments

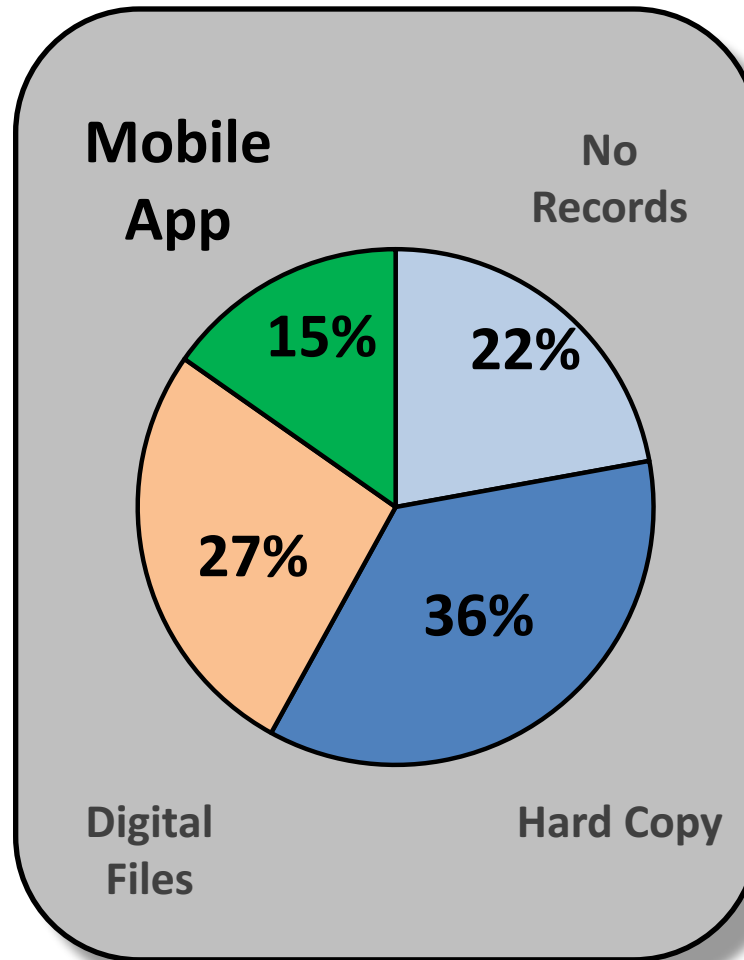
Johns Hopkins database of over 2000 mutations found D1152H
And now in a special JH study to find mutations on 3 other genes believed to affect CF.

I was checked for 10 mutations.
Now they check for 14 for most Israelis.

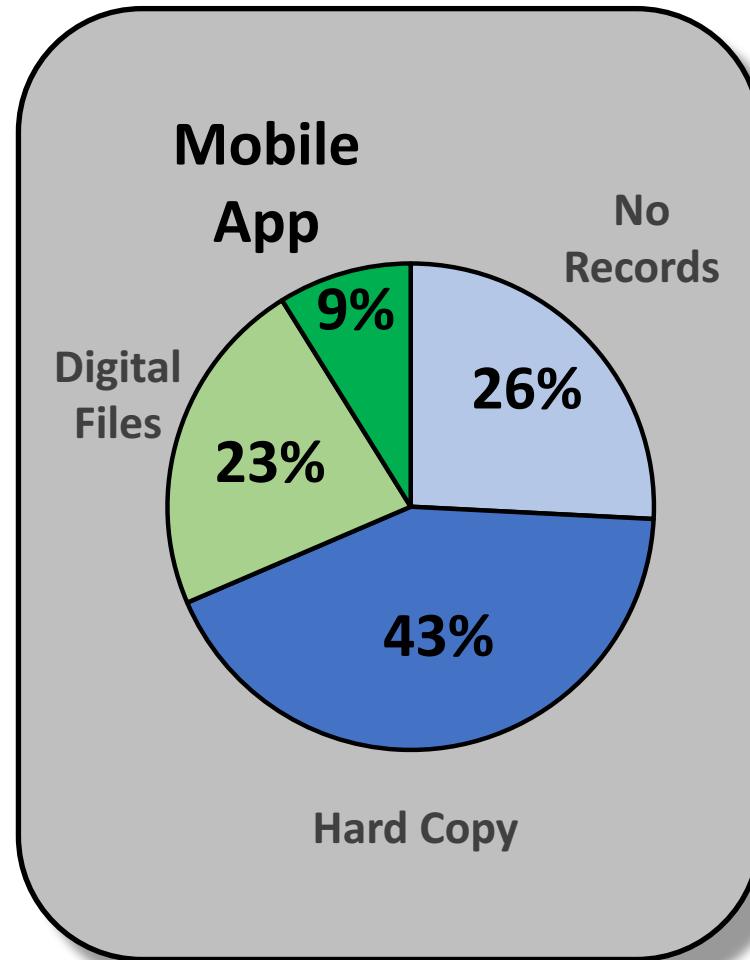
Unfortunately, in Pakistan only DDF508 mutation is available...
There are many patients who Don't know their mutations

multiple mentions possible

1 in 6 (15%) adult CF patients surveyed use at least 1 mobile app to keep medical test results and lifestyle/behavior info. Twenty-two percent (22%) keep no records at all.



Only 9% of caregivers of children with CF surveyed use at least 1 mobile app to keep medical test results and lifestyle/behavior info. Twenty-six percent (26%) keep no records at all.



Data privacy, security and monetization are significant issues.

	Adult CF Patient (n=616)	Caregiver of Child w/CF (n=502)	
<i>I would want to know if the app company sells my data</i>	68%	78%	↑
<i>I would stop using the app if my data was sold without my permission</i>	62%	74%	↑
<i>I would be concerned with the apps privacy policy</i>	52%	59%	↑
<i>I would be concerned about where the data is stored (i.e. private cloud)</i>	49%	53%	↑
<i>I would keep using the app if I received some of the revenue from data monetization</i>	49%	39%	↓

% agreeing with statement

Online survey; n= 616 adult cystic fibrosis patients,
n= 502 caregivers of children with CF. Data collected 10/17/2017-4/11/2018

What data are you already collecting or willing to collect?

Patients &
Caregivers
(n=1026)

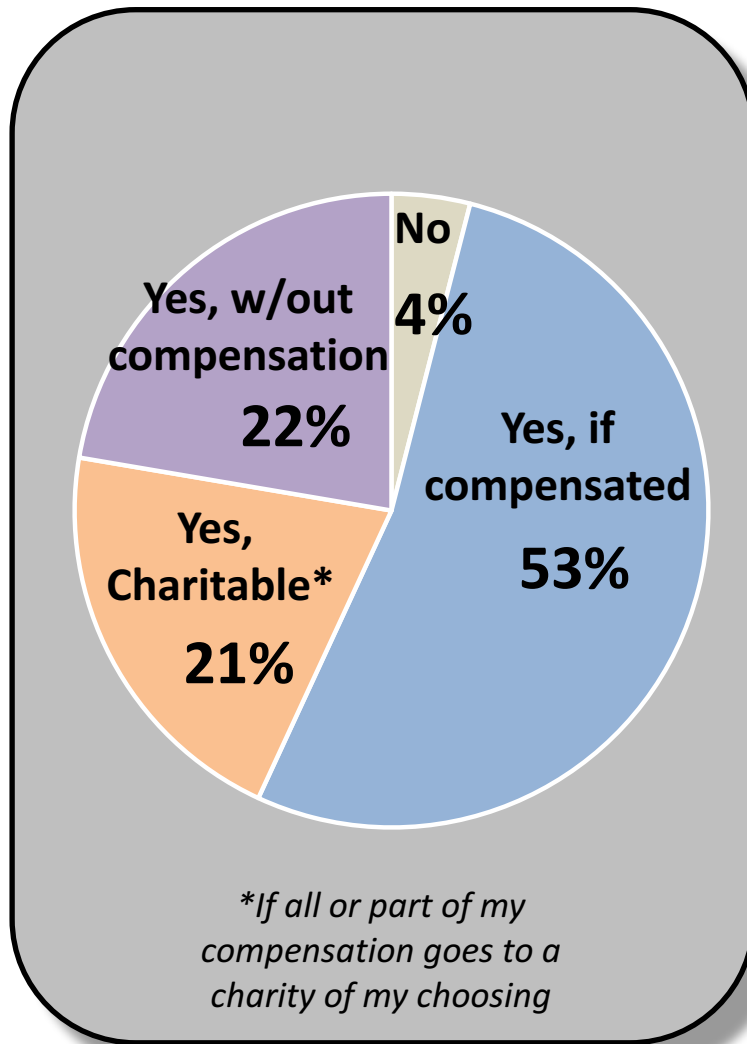
MEDICATION USE	84%
SPIROMETRY RESULTS (PFTS)	83%
CF GENETIC TEST RESULTS (YOUR MUTATIONS)	82%
LAB CULTURES (SPUTUM MICROBIOLOGY)	79%
HOSPITALIZATIONS	70%
EXERCISE	70%
DIETARY SUPPLEMENT, PROBIOTICS, AND VITAMINS	66%
MEDICATION DELIVERY SYSTEM USE (NEBULIZERS, IVS, G-TUBE)	65%
IN-HOME TREATMENTS	64%
NUTRITION	61%
QUESTIONNAIRES OF INTEREST TO INDUSTRY OR ACADEMIC LEADERS	52%
MICROBIOME ANALYSIS (LUNG OR GUT)	44%
AIR QUALITY AND POLLUTION DATA	43%
GENOME SEQUENCING DATA	42%
EXOME SEQUENCING DATA	34%

> 2/3

< 1/2

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Some medications result from precision medicine. To advance research like this, the medical community needs the data of people with CF. Are you willing to share your data?

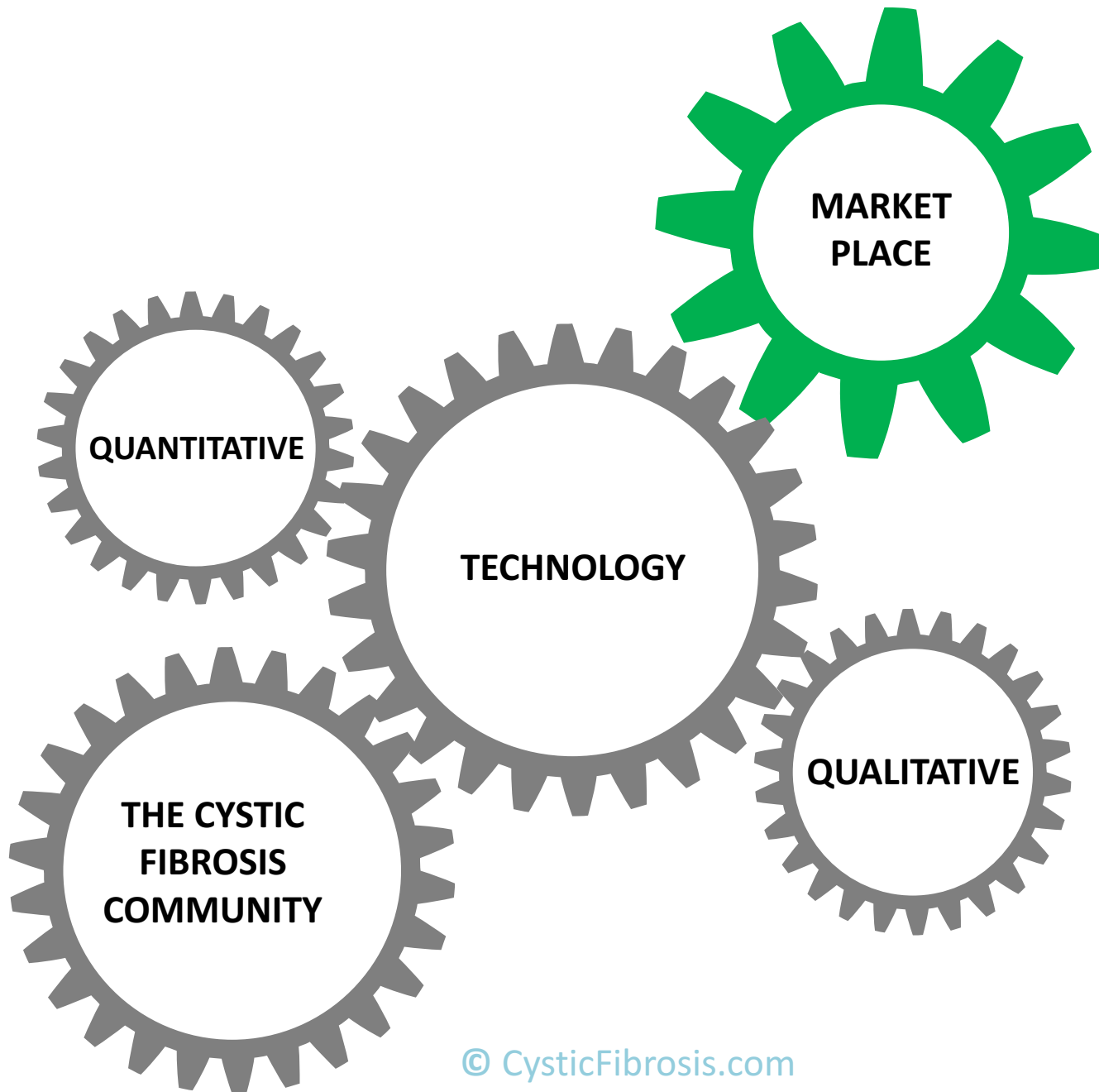


In Their Own Words...

"Depends on who gets the data and how they use it."

"Compensation does not have to be monetary. Assistance with treatment, at home equipment costs is always helpful."

"Private Industry is going to benefit financially and compensation levels the field. The potential wealth in genomic data is beyond comprehension."



My “Ah - ~~HAH~~” Moment...

1. Our research proved that Patients and Caregivers will share their data. That data is extremely valuable.
2. I have set before you a Unique Resource, a Community READY to join with the Technology they NEED.

They need programmers, money, and SUPPORT...

3. Let's build this app, collect their data...move it forward.

Let us know this is your AHA moment!



You are ready to chase after me and hence them...to take health care forward.

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THANK YOU! WORLD ORPHAN DRUG CONGRESS

Many people are EXCITED!

- This is an exciting concept to open communication between the actual creators/scientists and patients-without using the doctors as translators. They have enough work keeping is alive, we can't always expect them to ask all the right questions and pass on helpful info. As much research and care cf doctors and scientists do, they don't wake up every morning praying that the first breath they take won't be their last, then work all day to shatter the 'pred' value limits. I think this will open a new world of info and products to make our lives healthier and easier. THANKS!