RareConnect.org

A EURORDIS INITIATIVE

MARTA CAMPABADAL
RareConnect Manager

RareConnect.org in numbers

110
global communities

795
advocacy organizations

32K
members

8
languages
DE, EN, ES, FR, IT, PT, SR, RU

346
moderators

1,1M
visits/year

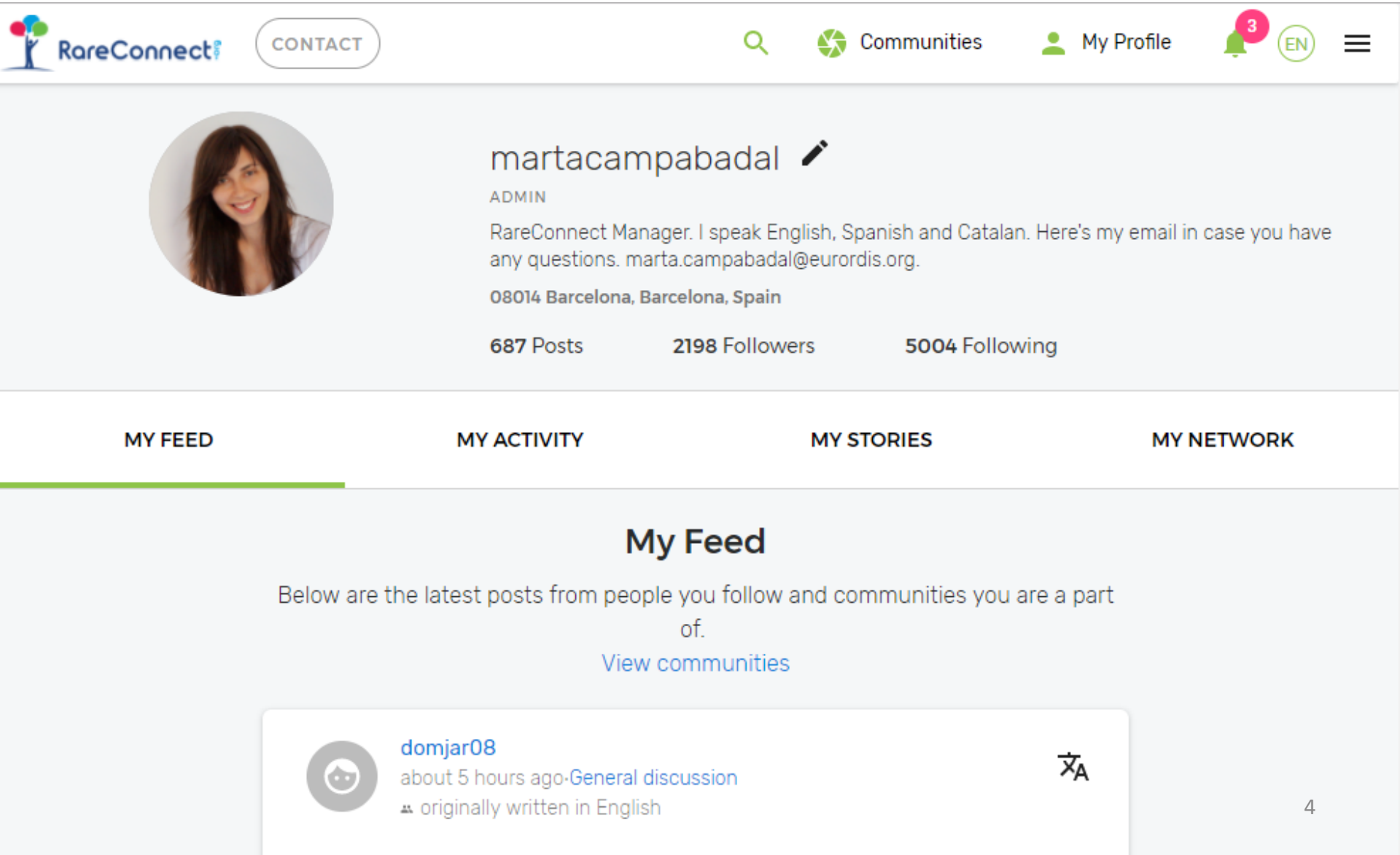
23K
posts

2K
patient testimonials

Partnership with SickKids Hospital

- Over 1 year of partnership and work
- In-house development team
- Give rapid response to users feedback
- Integrate RareConnect with PhenomeCentral

Differences between platforms



Differences between platforms

fully **adapted to mobile devices**
easier to use

new interface > new features

more intuitive and **user friendly**

Differences between platforms

New technology > cut hosting costs

More **secure** platform

Faster!

RareConnect | CONTACT | Communities | My Profile | EN

martacampabadal

ADMIN

RareConnect Manager. I speak English, Spanish and Catalan. Here's my email in case you have any questions. marta.campabadal@eurordis.org.

08014 Barcelona, Barcelona, Spain

687 Posts **2198** Followers **5015** Following

MY FEED | MY ACTIVITY | MY STORIES | MY NETWORK

My Feed

Below are the latest posts from people you follow and communities you are a part of.
View communities

sisterwaller
about 4 hours ago-Trimethylaminuria
originally written in English

I must start by saying I haven't been diagnosed with this condition but I surely have all the symptoms. I was in fifth grade when I noticed how people treated me differently. Know one would sit beside me for very long. At lunchtime i was always alone. I had a best friend since, I guess you don't notice much at that age We'll to make along story short. I really notice my problem when I got my first job. I never kept a job for long. I could never get a

Read More

2 LIKES 1 REPLY

Porphyria-FAQs

Porphyria drugs safe list

The Welsh Medicines Information Centre (WMIC) offers a specialist advisory service on the safe use of drugs in porphyria.

https://www.wmic.wales.nhs.uk/specialist-services/drugs-in-porphyria/

Read More

EN

Notifications


tihana liked your post
about 3 hours ago


tihana liked your post
about 3 hours ago


tihana liked your post
about 3 hours ago


tihana liked your post
about 3 hours ago

angelsalcaraz liked your post
about 11 hours ago

angelsalcaraz liked your post
about 12 hours ago


tihana liked your post
about 22 hours ago

nathaliegiroux commented on a post you also commented on

RareConnect maps

Find others in their country and connect through private messaging while also allowing patient groups to get an idea of what the worldwide **distribution of patients** looks like

Members can choose to share no location, or only country, don't have to share city.

As always, members don't have to put their real name and can use a **pseudonym**.


Map
Satellite
Person
Organization
Finland
Iceland
Sweden
Norway
Russia
Poland
Germany
Ukraine
France
Italy
Spain
Turkey
Kazakhstan
Mongolia
Afghanistan
Iraq
Iran
Pakistan
Saudi Ara
South Kore
Thailand
Indonesia
Papua
Algeria
Libya
Mali
Niger
Chad
Sudan
Nigeria
Ethiopia
R Congo
Tanzania
Angola
Namibia
Botswana
Madagascar
South Africa
United S
Mexico
Venezuela
Colombia
Brazil
Bolivia
Chile
Argentina
North Atlantic Ocean
South Atlantic Ocean
South Pacific Ocean
Indian Ocean
21
167
4
30
67
398
39
50
2
6
52
17
18
29
147
79
42
7
9
11
33
20
Google
Map data ©2017
Terms of Use

Language shouldn’t be a barrier

manual request translation

automatic machine translation

had276
about 12 hours ago · Trimethylaminuria
originally written in French

francophone

Hello everyone, are there any francophones here? leave a comment if you are interested in a discussion. Thank you

LIKE 1 REPLY

aysberg20
about 1 hour ago
originally written in tr

I am interested in

LIKE

had276
il y a environ 12 heures · Triméthylaminurie
Rédigé à l'origine en Français

Francophone

Bonjour à tous , y a t-il des francophones ici? laissez vos coordonnées en commentaire si vous êtes intéressé par une discussion. Merci

LIKES 1 RÉPONDRE

aysberg20
il y a environ 1 heure
Rédigé à l'origine en tr

je suis intéressé

LIKES

Volunteer translators

OneSky

LANGUAGE	TRANSLATED
en English	
es Español	
fr Français	
Hrvatski	
Italiano	
pt Português	
ru Русский	
日本語	
de Deutsch	
el Ελληνικά	
fa فارسی	

Send us email at **info@rareconnect.org**

Profiles for patient organisations

- Share events
- Reach people worldwide
- Share updated information, clinical trials, crowdfunding campaigns…
- Promote the organisation's activities

Cooming soon! New features for patient organisations

Create your RareConnect Account

Welcome to the registration section of RareConnect.org. In just a few simple steps you will join the supportive social network for rare disease patients. Look around, join a community and get connected! If you already have an account, please click the log in link below.

Log in

I am a...

Person

Connect with others who understand you. Learn about research and the latest treatments. See what advocacy organizations are doing around the world. Find helpful resources and information from experts.

Organization

Patient organizations are integral to the success of RareConnect. We rely on patient organizations to help provide disease expertise and share information about their programs, services, and events.

General Discussion Community

General Discussion Community

“This global community is the space where all RareConnect members can discuss general topics that are not specific to a particular community. If you want to ask or share something about patient advocacy, research, events, orphan drugs, gene therapy… do it here!”

domjar08

5 days ago·General discussion

originally written in English

Jarid1C

My family member has a rare disease associated with Syndrome X but it is not fragile X. The disease is quite rare and symptoms vary. Physicians and Specialists know little of this genetic abnormality. Do you have any members with this condition.?

2 LIKES 2 REPLIES

juanatano

22 days ago·General discussion

originally written in English

I do not know how to help friends who suffer from anxiety and depression. Does anybody have any recommendations?

LIKE 1 REPLY

_hannahmt

8 days ago·General discussion

originally written in English

Support in Italy

Hi guys, I'm looking for a community for muscular dystrophy patients in Italy. I am interested in Orphan Drug accessibility for patients. Does anyone have any recommendations o contacts for me? Thank you for your help!

marairenebenavidesguillm

13 days ago·General discussion

originally written in Spanish

Hi. I invite you to visit my page and tell me what you think. Your opinion is very important to me. Thank you. Blessings.
https://sites.google.com/site/pemerac/

1 LIKE REPLY

ellyn

5 days ago·General discussion

originally written in English

3p13 duplication

Hi I'm I
duplica
on mor
Thank

martacampabadal

17 days ago·General discussion

originally written in English

Unique (Understanding Chromosome Disorders) on Social Media

For a list of the local groups, across the UK, Europe, North America, Australia, New Zealand and many others, click the link below or email marion@rarechromo.org for details.

http://www.rarechromo.org/files/facebooksocialnetworking.pdf

3 LIKES 1 REPLY

What are the ‘Looking for’ calls?

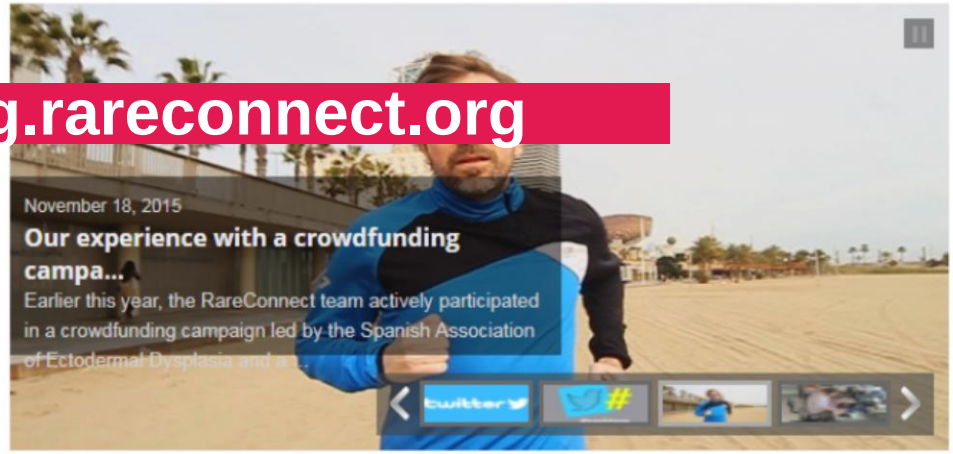
What are the ‘Looking for’ calls?

Receive monthly updates

These monthly updates include:

- newest RareConnect communities
- communities in the pipeline
- new features
- recent calls posted on the **General Discussion** community
- other news about EURORDIS & RareConnect

blog.rareconnect.org



Latest Posts

Redes sociales para pa...
September 3 - no comments

El pasado mes de Junio 2017 nos invitaron a hablar de redes sociales y RareConnect en la 1a Escuela ...

How do I set up a pati...
August 24 - no comments

Many people that visit RareConnect are interested in starting a formal rare disease patient organiza...

21 ways to participate...
February 17 - 7 comments

Caring for people living with a rare disease has many facets. Some patients have access to medicines...

Get the latest RareConnect updates

October 15, 2017 - Promoting RareConnect - no comments

Once a month we send updates with the latest RareConnect news in English and Spanish. Do you want to start receiving them? Fill in the form below! We'd love to...

Read Post →

Plant a flag!

Share Buttons

Join us here!

Follow us on Twitter.

Like us on Facebook

Contact us

Search

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Select Language

Recent Posts

- Get the latest RareConnect updates
- Plant a flag!
- Redes sociales para pacientes e investigadores
- How do I set up a patient organisation for my rare disease?
- 21 ways to participate in International Rare Disease Day 2017

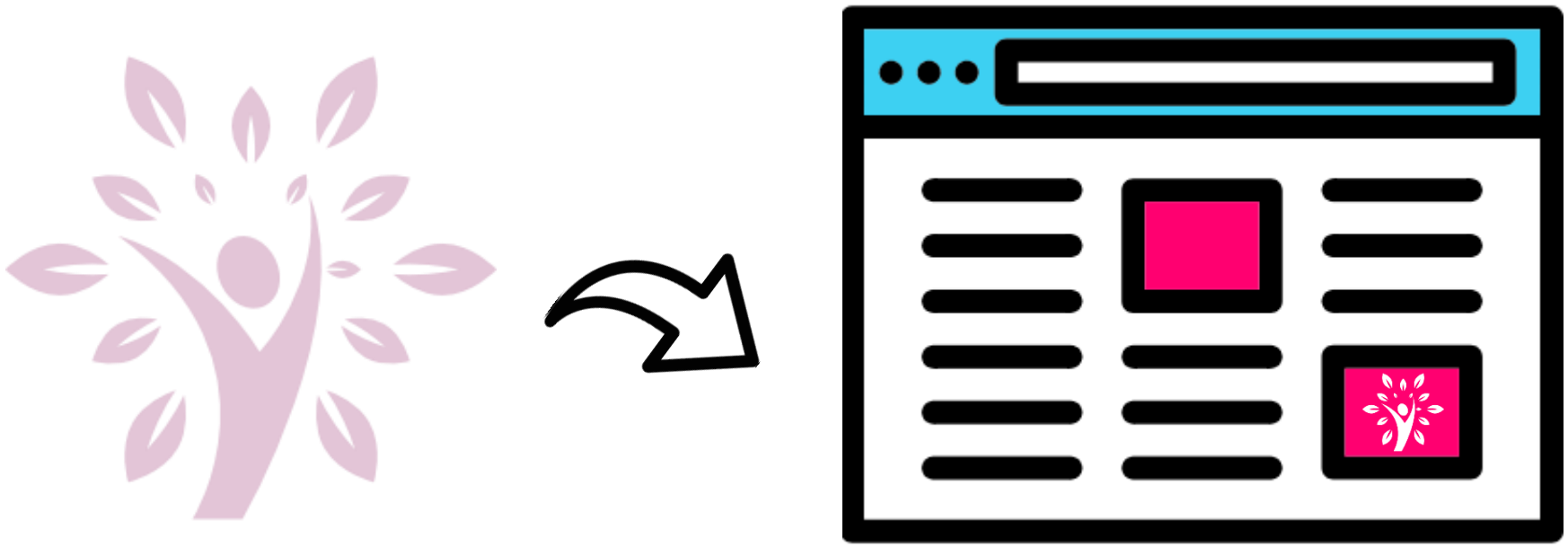
Send us email at **info@rareconnect.org**

How can the National Alliances take part?

Some easy steps:

- Sign up and fill in your profile
- Join one or more communities
- Post updates on your profile
- Post calls on the General Discussion community
- Participate in decision making processes
- Encourage your members/audience to join the conversation
- Add the RareConnect logo to your website
- Send us your logo too!

Featured National Alliances in our homepage



Future plans for the platform

PHENOTIPS™

CARE forRARE

RD Connect

Future plans for the platform

PHENOTIPS®

Fork me on GitHub

Home | Playground | Download | Documentation ▼ | Contribute ▼ | Contact | Intranet login

PhenoTips® is a software tool for collecting and analyzing phenotypic information of patients with genetic disorders.

- **Free** and open source
- **Web**-based application
- Easy to **customize**

- **Standardized phenotyping** using the Human Phenotype Ontology (HPO)
- **Error-tolerant, predictive search** of the ontology
- Real-time evaluation of the **informational value of the phenotypic description** via the Monarch Phenotype Profile Analysis
- Powerful built-in **pedigree editor**
- Measurements and **growth curves**
- **Diagnosis assistance** based on the entered data

NEWS

Aug 23, 2017
PhenoTips 1.4 Milestone 1 Released

Jul 24, 2017
PhenoTips 1.3.2 (stable) Released

Jun 19, 2017
PhenoTips 1.3.1 (stable) Released

May 01, 2017
PhenoTips 1.3 (stable) released

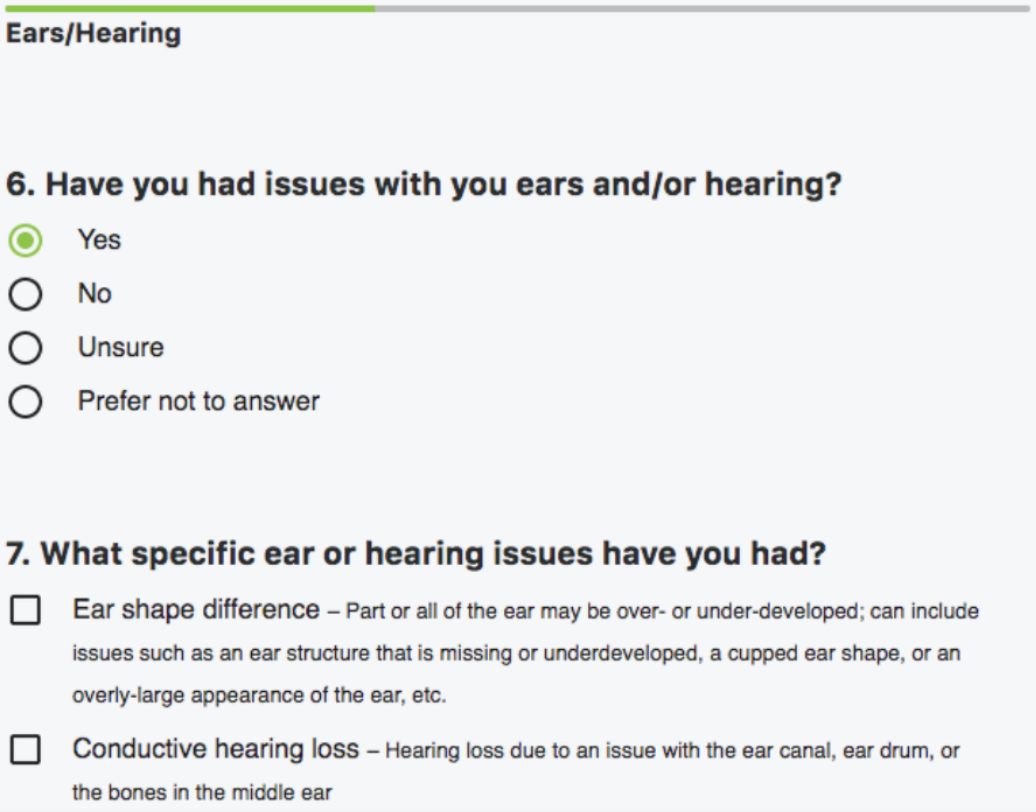
Mar 22, 2017
PhenoTips 1.3 Release Candidate 3 Released

Mar 21, 2017
PhenoTips 1.3 Release Candidate 2 Released

Mar 20, 2017
PhenoTips 1.3 Release Candidate 1 Released

Study questionnaires

Patients can self-describe & do questionnaires



Ears/Hearing

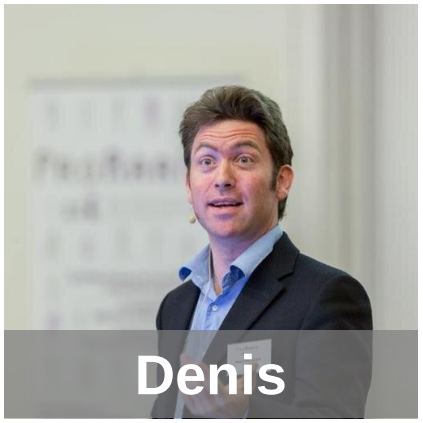
6. Have you had issues with you ears and/or hearing?

- (●) Yes
- ( ) No
- ( ) Unsure
- ( ) Prefer not to answer

7. What specific ear or hearing issues have you had?

- [ ] Ear shape difference – Part or all of the ear may be over- or under-developed; can include issues such as an ear structure that is missing or underdeveloped, a cupped ear shape, or an overly-large appearance of the ear, etc.
- [ ] Conductive hearing loss – Hearing loss due to an issue with the ear canal, ear drum, or the bones in the middle ear

RareConnect support staff



Contact us!

Where to find us…

 info@rareconnect.org

 facebook.com/rareconnect

 @rareconnect

 rareconnect