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(PAUL HEATH)

What is it?

- Group of healthcare professionals with an interest in cCMV
- Initially group of Paeds ID doctors in ESPID but widening to others
- cCMVnet registry/database aiming to join the previous UK & Spanish registries

What do we do?

- Recruit participant to the cCMVnet registry
- Monthly cCMV virtual “clinic”- Discuss tricky cases (next is tomorrow!)
- Education (HCP & public)- website development in progress
- Research- directly using data from registry but also aiming to undertake other research (funding ideas...just received 20,000 euros from ESPID for database management)

DATABASE: MEMBERS

MEMBERS IN cCMVNet

TOTAL NUMBER OF MEMBERS:

58

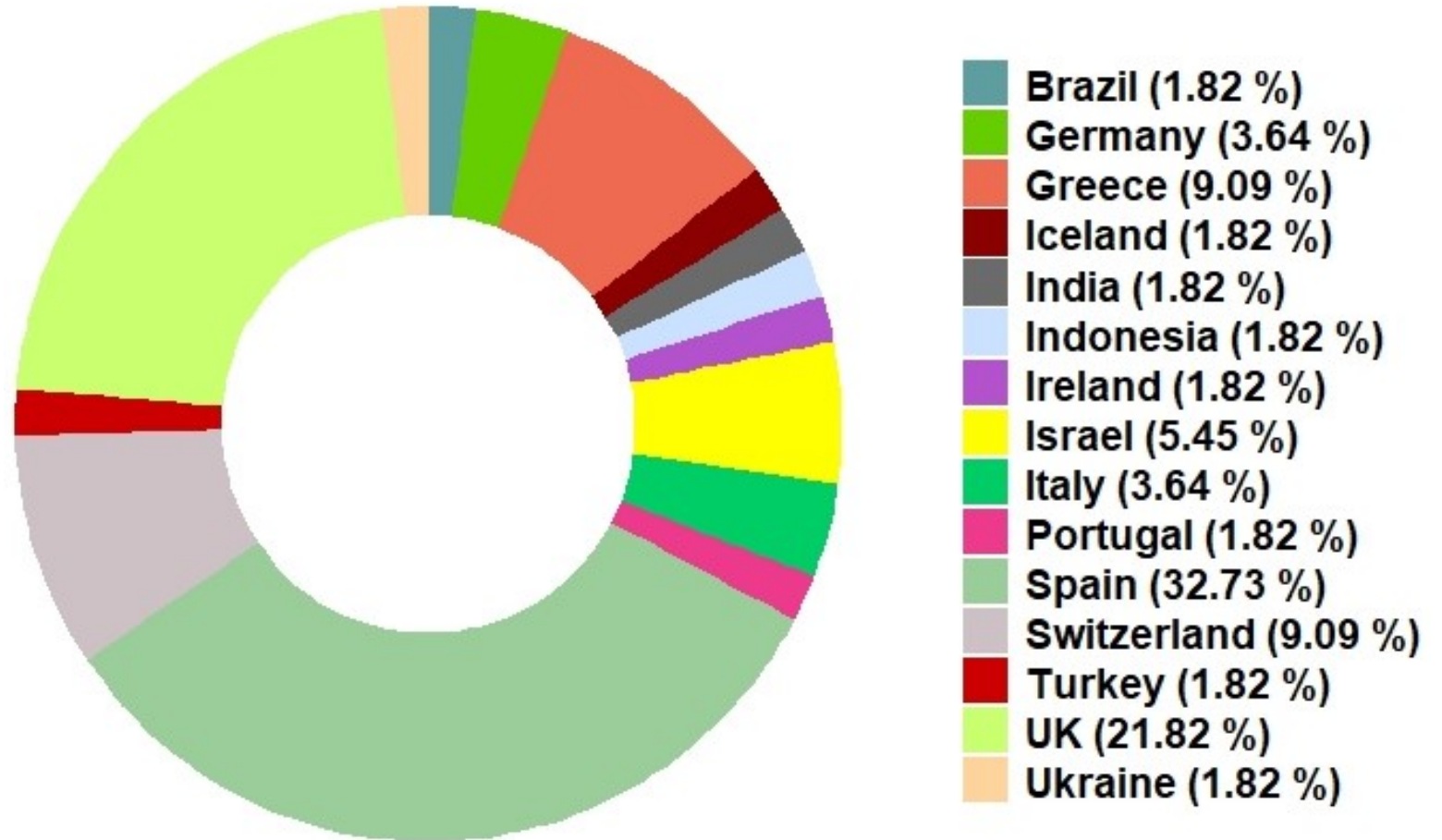
NUMBER OF PATIENTS :

715

Spain

12

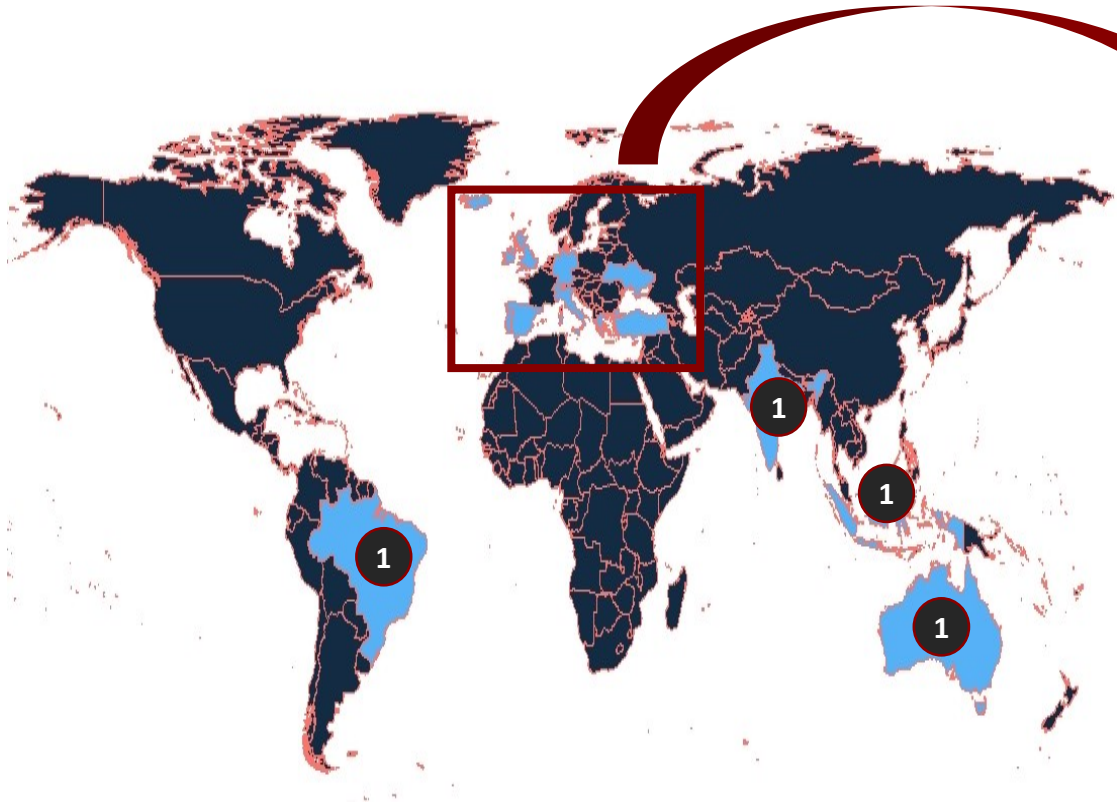
**Others
(pending
update n=100)**



PID, audiologists, virologists, microbiologists, etc

DATABASE: INSTITUTIONS

50 INSTITUTIONS FROM 17 COUNTRIES



INSTITUTIONS WITH IRB APPROVAL:
Spain (network), Greece (2)





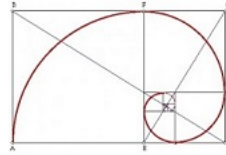
cCMVnet database

- ✓ **Approved** by 12 de Octubre Hospital (Madrid, Spain) **Ethics Committee (October 2020)**
(NB: needs approval in each country to recruit patients)
- ✓ **Informed consent**
- ✓ **External reviewers**
- ✓ **REDCap database**
 - ✓ Based on Spanish and ECCI-UK databases
- ✓ **cCMVnet Authorship agreement**
- ✓ **Data management**
 - ✓ Estrella Esquivel (Bioinformatics/Statistician)

cCMV registry

- UK ethics being completed, aiming to submit in next few weeks
- Retrospective & prospective recruitment of infants with PROVEN cCMV
- (ECCI database plans....)
- To join network +/- participate in recruitment: simon.drysdale@nhs.net

Log In



Unidad de Investigación y Soporte Científico

Please log in with your user name and password. If you are having trouble logging in, please contact [Administrador](#).

Username:

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✓ Password

Welcome to REDCap!

REDCap is a mature, secure web application for building and managing online surveys and databases. Using REDCap's stream-lined process for rapidly developing projects, you may create and design projects using 1) the online method from your web browser using the Online Designer; and/or 2) the offline method by constructing a 'data dictionary' template file in Microsoft Excel, which can be later uploaded into REDCap. Both surveys and databases (or a mixture of the two) can be built using these methods.

REDCap provides automated export procedures for seamless data downloads to Excel and common statistical packages (SPSS, SAS, Stata, R), as well as a built-in project calendar, a scheduling module, ad hoc reporting tools, and advanced features, such as branching logic, file uploading, and calculated fields.

Learn more about REDCap by watching a [brief summary video \(4 min\)](#). If you would like to view other quick video tutorials of REDCap in action and an overview of its features, please see the [Training Resources](#) page.

NOTICE: If you are collecting data for the purposes of human subjects research, review and approval of the project is required by your Institutional Review Board.

If you require assistance or have any questions about REDCap, please contact [Administrador](#).

REDCap Features

Build online surveys and databases quickly and securely - Create and design your project rapidly using secure web authentication from your browser. No extra software is required.

Fast and flexible - Conception to production-level survey/database in less than one day.

Export data to common data analysis packages - Export your data to Microsoft Excel, PDF, SAS, Stata, R, or SPSS for analysis.

Ad Hoc Reporting - Create custom queries for generating reports to view or download.

Scheduling - Utilize a built-in project calendar and scheduling module for organizing your events and appointments.

Easily manage a contact list of survey respondents or create a simple survey link - Build a list of email contacts, create custom email invitations, and track who responds, or you may



Thank you