## **IMBS** Patient Registry



IMBS Alliance in collaboration with CoRDS (Sanford Research)



# CORDS



#### Contact

- IMBS Alliance
  - www.imbs-alliance.org
  - registry-support@imbs-alliance.org
- CoRDS
  - <a href="https://research.sanfordhealth.org/rare-disease-registry">https://research.sanfordhealth.org/rare-disease-registry</a>
  - cords@sanfordhealth.org

#### Who is this patient registry for?

- All patients that show chronical and abnormal body odor (bromhidrosis) and/or bad breath (halitosis)
- This explicitly includes a wide variety of possible odor types such as:
  - Fecal odor
  - Smelly cheesy feet odor
  - Vomit odor
  - Rotten eggs odor
  - Urine odor
  - Fishy odor
  - Rotten/dead meat odor
  - •
- This explicitly includes TMAU and SELENBP1 patients of all types

### How will this patient registry support us?

- As one of the first official patient registries that is available it has the potential to
  - reveal the huge number of patients affected by IMBS to the medical research community
  - establish the first sets of potential biomarkers which need a research focus
  - reveal statistical information about the distribution of the different body odor types/subgroups
  - reveal correlations with e.g. IBS (Irritable Bowel Syndrome)

#### Personal data protection

- The data is collected and stored in the CoRDS patient registry platform
  - https://research.sanfordhealth.org/rare-disease-registry
- The CoRDS platform follows strict protection rules and the participant has all options to decide what happens to his/her data
- For more details, please take a look at the CoRDS FAQ (<a href="https://research.sanfordhealth.org/rare-disease-registry/frequently-asked-questions">https://research.sanfordhealth.org/rare-disease-registry/frequently-asked-questions</a>)

#### What do patients have to do?

Enroll yourself within the patient registry! (most important)

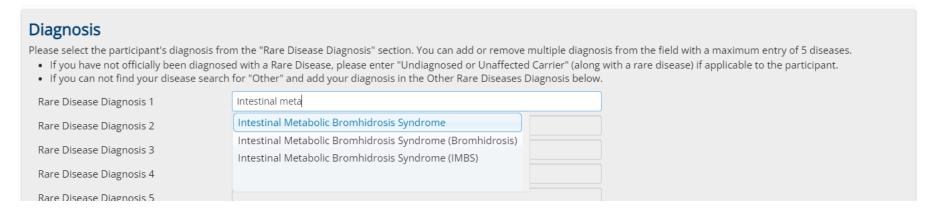
Here is the link:

https://cordsconnect.sanfordresearch.org/BayaPES/sf/screeningForm?id=SFSFL

Very important:

select "Intestinal Metabolic Bromhidrosis Syndrome" on the first registration

page



• Share this PDF with other patients, so that we reach the whole community and no one gets left behind!!!