

IMBS Patient Registry



IMBS Alliance in collaboration with CoRDS (Sanford Research)



CoRDS

SANFORD
RESEARCH



Contact

- IMBS Alliance

- www.imbs-alliance.org
- registry-support@imbs-alliance.org

- CoRDS

- <https://research.sanfordhealth.org/rare-disease-registry>
- cords@sanfordhealth.org

Who is this patient registry for?

- All patients that show chronic 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
(<https://research.sanfordhealth.org/rare-disease-registry/frequently-asked-questions>)

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**

Diagnosis

Please select the participant's diagnosis from the "Rare Disease Diagnosis" section. You can add or remove multiple diagnosis from the field with a maximum entry of 5 diseases.

- If you have not officially been diagnosed with a Rare Disease, please enter "Undiagnosed or Unaffected Carrier" (along with a rare disease) if applicable to the participant.
- If you can not find your disease search for "Other" and add your diagnosis in the Other Rare Diseases Diagnosis below.

Rare Disease Diagnosis 1	<input type="text" value="Intestinal meta"/>	
Rare Disease Diagnosis 2	<input type="text" value="Intestinal Metabolic Bromhidrosis Syndrome"/>	<input type="text"/>
Rare Disease Diagnosis 3	<input type="text" value="Intestinal Metabolic Bromhidrosis Syndrome (Bromhidrosis)"/>	<input type="text"/>
Rare Disease Diagnosis 4	<input type="text" value="Intestinal Metabolic Bromhidrosis Syndrome (IMBS)"/>	<input type="text"/>
Rare Disease Diagnosis 5	<input type="text"/>	<input type="text"/>

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