



Rare Bone Disease Summit



RBD Summit 2021 Partners

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We are delighted to announce that the first Rare Bone Disease (RBD) Summit officially took place in December 2021 and was a resounding success.

The RBD Summit was a two-day, global, multi-stakeholder group meeting aiming to enable contributors working in the RBD field to collaborate towards improving the lives of patients living with these conditions.

This is planned to be an annual event. The format and organization of the summit will evolve each year based on ongoing discussions with a shared goal towards improving the lives of patients living with RBD.

RBD Summit 2021 at a glance:



65
Attendees



**Multi-Stakeholder
Representatives**



4
Continents Covered



3
Parallel Workshops

Including patient organizations, medical and scientific societies, medical education providers, and pharmaceutical companies, as well as other expert healthcare professionals.

Addressing unmet needs

On Day 1 of the meeting, contributors took part in one of three parallel workshops tackling three areas of unmet need, including:

- Overcoming obstacles to diagnosis: Improving awareness of RBDs
- Optimizing care pathways by implementing person-centered care pathways (PCCP)
- Narrowing the communication gap between patients and healthcare professionals

The day concluded with engaging sessions to identify solutions that could overcome the barriers in these areas of RBD care.

Identifying and prioritizing actions for 2022 and beyond

Day 2 focused on creating and prioritizing action items and included captivating and insightful discussions about how these actions could lead to initiatives driven by the multi-stakeholder group to ensure improved outcomes for patients living with rare bone conditions.

Discussions and proposed actions from the two-day Summit were grouped into the following four categories:



Leverage digital health



Improving RBD awareness and education



Removing silos and working collaboratively



Guidelines

What's next?

The RBD Summit steering committee, which is made up of representatives from international patient organizations, leading RBD expert physicians and 4 pharmaceutical companies will meet throughout 2022 to assign roles and responsibilities for the actions and plan the next steps.

Plans are also underway to publish a white paper article about the outcomes from the Summit and to submit these outcomes to key conferences.

We have been privileged to be involved in this important and unique collaboration between industry, academia, clinical and patient communities that will drive tangible outcomes to help tackle the challenges of RBDs and ultimately improve the lives of patients.

To learn more about the initiative, you can visit www.rbdsummit.com

Yours sincerely,

The RBD Summit Steering Committee

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