

## Invite letter to Young People's Forum for PKU

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Dear PKU Foreningen Danmark,

Thank you for your interest in participating in PTC Therapeutics' new initiative to create a Young People's Forum (YPF) for PKU.

### **Why is PTC interested in a Young People's Forum for PKU**

PTC is a biopharmaceutical company focused on Rare Disease. The PTC Patient Advocacy team wishes to partner with the PKU community to ensure that the patient voice is incorporated into the development of resources and initiatives designed to support patients and caregivers living with PKU.

### **What is the Young People's Forum**

This Forum is designed for young people aged 18-30 living with PKU. It offers a great opportunity to connect with peers across Europe and the Middle East, where participants can share experiences and explore innovative solutions to the challenges faced by those in the PKU community.

Specifically, the Forum seeks to provide a place to:

- **Share Your Journey:** Your experiences are invaluable. Help us understand the everyday challenges of PKU and drive change by highlighting what truly matters.
- **Build Meaningful Connections:** Connect and communicate with peers to create a strong transparent partnership
- **Collaborate on What's Next:** Be part of the team creating resources and initiatives that will guide and help people living with PKU around the world

### **Who we are looking for**

- People **aged 18–30** living with PKU anywhere in Europe and the Middle East,
- Ability to confidently converse in English in order to take part in group conversations,
- Willing to participate in quarterly online meetings and one group face-to-face meeting in Spring 2026

The forum will include about **12–15 members** from a number of different countries so that a diversity of voices can be heard.

### **What joining involves**

As a participant of the YPF, you would be starting off with a 20-30 min onboarding call where you would be able to ask any questions you may have about the forum. After that, you would be required to attend a quarterly on-line meeting (3 hours) commencing in December 2025 and a full day in-person meeting in early 2026.

Between meetings we may share short reading or surveys to help prepare for future discussions.

### **More details about participation/membership**

As a member you would:

- Share experiences and ideas that could benefit the wider PKU community,
- Respect the confidentiality of fellow participants, and
- Stay open to an ongoing dialogue.

In return, you will receive:

- An opportunity to connect with other young PKU advocates from across Europe and the Middle East to network, build relationships, share knowledge and develop leadership and communication skills.
- An honorarium for each meeting (aligned with patient engagement guidelines for your home country),
- Full reimbursement of travel, accommodation and meal costs for the annual face-to-face workshop, and
- Written summaries of the forum's outcomes so you can report back to peers or patient organisations.

#### Note:

*PTC will work with admedicum, an agency that specialises in patient engagement. Admedicum will support the logistical aspects of forum management. All personal data will be processed in line with EU GDPR requirements, and you are free to withdraw at any time without giving a reason.*

### **Next steps**

If you are interested, please let us know by **08/12/2025** and we will schedule a short onboarding call to answer any questions and confirm practical details.

**Contact Robert, the admedicum project manager in charge of recruitment:  
Robert.pleticha@admedicum.com**

Or e-mail **Davor Duboka** at **dduboka@ptcbio.com** with any questions you may have.

We would be honored to work with you to make a positive difference for people living with PKU.

Thank you very much for considering this invitation.

Warm regards,

Davor Duboka  
*Associate Director, Patient Advocacy  
PTC Therapeutics*