

# Family course on sickle cell disease

September 8–12, 2025 at Frambu

Meet others with sickle cell disease

Health care professionals give lectures

Free of charge

Parents are given paid leave from work

The whole family stays at Frambu



Foto: Adobe Stock

Senter for sjeldne diagnoser  
[www.sjeldnediagnoser.no](http://www.sjeldnediagnoser.no)

**The Center for Rare Disorders invites your family to a free family course on sickle cell disease.**

### Who can participate?

**Children and youth** with sickle cell disease born in 2010 or later, together with their guardians and siblings.

### When is the family course?

Starts: Monday, September 8, 2025 at 10:30 AM

Ends: Friday, September 12, 2025 at 1:15 PM

### Finance

**The course and stay are free.**

Travel expenses are covered by Pasientreiser.

Working parents receive training funds. Those who join the course will receive more information about this.

### What does the course include?

The course offers children, youth, and parents the opportunity to learn more about the diagnosis, get answers to their questions, and share experiences with others in similar situations.

It gives counselors and physicians at the Center for Rare Disorders a better understanding and increases their knowledge of the condition.

Topics on the course:

- Information about diagnosis and treatment
- Special arrangements in kindergarten/school
- Rights related to the disease
- Physical activity and nutrition
- The impact of the disease on family life
- Groups discussions

### Parents

The course is organized as a combination of lectures, dialogue and group discussions. The course program will be based on the topics above and any questions you have written on the application form.

### Children and adolescents

Children and adolescents attend Frambu's preschool or school while their parents participate in lectures. There will be enjoyable activities together with other children, youth and siblings. You will work on some of the same topics as the adults.

### Where is Frambu located?

Frambu Resource Center for Rare Disorders is located just outside Oslo.

Address: Sandbakkveien 18, 1404 Siggerud

### Watch videos and pictures from Frambu

Read more about Frambu, watch videos and view photos from previous courses.

Frambus website have a google translation on the top of their site.



[frambu.no](https://frambu.no)

### Evening activities at Frambu

Frambu has a fantastic outdoor area where the families can enjoy various activities.

In the afternoons and evenings, there are joint activities indoors and outdoors:

- Hikes and other outdoor activities
- Gaming, playing table tennis and other "indoor games"
- Watching films
- Various creative activities
- Heated pool

### Apply before May 24, 2025

**You can apply digitally, go to:**

[www.sjeldnediagnoser.no](https://www.sjeldnediagnoser.no) → *Kurs og arrangementer*

→ *Personer med en sjelden diagnose og pårørende*

→ *Sigdcellesykdommer*

Alternatively, the QR code below

Or **by post**: See the last page.

You will receive a response to your application at the end of June.

### Lunch webinars for professionals

On Wednesday October 15, we will be hosting a webinar for health personnel who provide follow-up for the children. Give the attached invitation or send the link, see the QR below and click on "Lunsjwebinar", to those you wish to attend.

We encourage everyone to invite professionals, whether or not you will be attending the course.

### Questions?

Tel: 23 07 53 40

Website: [www.sjeldnediagnoser.no](https://www.sjeldnediagnoser.no)



[sjeldnediagnoser.no](https://sjeldnediagnoser.no)

# Application form

Family course on sickle cell disease, week 37, 2025

Apply before May 24, 2025

WRITE WITH CAPITAL LETTERS!

**Name** on the person with the diagnosis: \_\_\_\_\_

Date of birth: \_\_\_\_\_

Address: \_\_\_\_\_

Postalcode: \_\_\_\_\_ City: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

**Guardians/parents who wish to attend the course:**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Mobile: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Mobile: \_\_\_\_\_

**Siblings who wish to attend the course**

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

**Interpreter**

Do you need an interpreter for the lectures? Yes ☐ No ☐

If yes, which language and dialect? \_\_\_\_\_

## Send in questions in advance

Please, fill out the last page of the application form. Then we can include the answers to your questions in the lectures and activities during the course. The program will be posted on [sjeldnediagnoser.no](http://sjeldnediagnoser.no) one week before the course starts and handed out upon arrival.

## Questions from the adult

1. Questions related to the topics presented above

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2. Other questions

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## Questions from the children and youth

Questions the child/youth with the diagnosis hope to get answered during the course:

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Questions the siblings hope to get answered during the course:

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Date: \_\_\_\_\_ Signature: \_\_\_\_\_

By post:  
Senter for sjeldne diagnoser,  
Oslo universitetssykehus HF,  
Rikshospitalet,  
Postboks 4950 Nydalen  
0424 Oslo  
Mark with "Gjelder kurs"