

Protonresan (your proton journey)

A virtual visit before your treatment period in Uppsala.



Watch the videos again and show them to loved ones who didn't get to see them in the VR headset at the clinic. You will find all seven videos at protonresan.barncancerfonden.se or by scanning the QR code.



Questions and answers about the treatment period in Uppsala.

When your child receives proton therapy, treatment takes place at Skandionkliniken in Uppsala. The treatment period is about six weeks. During this time, many people are offered the opportunity to stay at Ronald McDonald Hus. Akademiska barnsjukhuset, the Uppsala University children's hospital, is medically responsible during the treatment period in Uppsala. The hospital also has a hospital school and play therapy.



When you and your child arrive in Uppsala

Where do we go when we arrive in Uppsala? What address do we go to?

Here are the addresses of the specific locations in Uppsala:

- 1. Skandionkliniken**
von Kraemers allé 26
752 37 Uppsala
- 2. Ronald McDonald Hus**
Blåsenhusgatan 6
752 37 Uppsala
- 3. Uppsala Akademiska barnsjukhus** (and the hospital school and play therapy)
Dag Hammarskölds Väg, entrance 95.
751 85 Uppsala



- **Is it far to go between Skandionkliniken, Ronald McDonald Hus and Akademiska barnsjukhuset?**

No, there is just a few minutes' walk between Skandionkliniken, Ronald McDonald Hus and Akademiska barnsjukhuset.

- **How far is it from Uppsala central station to Skandionkliniken, Ronald McDonald Hus and Akademiska barnsjukhuset?**

It is 1.5 kilometre from Uppsala central station to Skandionkliniken, Ronald McDonald Hus and Akademiska barnsjukhuset, if you walk.

- **Where can I park if we take our own car?**

There are parking spaces next to Skandionkliniken, Ronald McDonald Hus and Akademiska barnsjukhuset, but a limited number. You can see the parking spaces on this overview map.



- **Are Skandionkliniken and Akademiska barnsjukhuset the same organisation?**

No, Skandionkliniken and Akademiska barnsjukhuset are different organisations.

- **What will happen on our first day in Uppsala?**

You and your child must be on site in Uppsala before treatment starts, for preparations and examinations. You will receive information on times and places for the first day from your child's regional paediatric oncology centre or Skandionkliniken.

- **Do we go to Skandionkliniken or Akademiska barnsjukhuset first?**

If your child needs to be sedated for radiation treatments at Skandionkliniken, you will have a doctor's appointment at Akademiska barnsjukhuset before the first treatment. After that, sedation and recovery will occur at Skandionkliniken in connection with the radiation treatments.

If your child does not need sedation, go directly to Skandionkliniken for the radiation treatment. The doctor in charge at your child's regional paediatric oncology centre or home hospital will tell you if your child needs to be sedated or not.

- **Can we borrow a wheelchair or stroller during our stay in Uppsala?**

Yes, there are limited options to borrow strollers and wheelchairs from Akademiska barnsjukhuset or from Ronald McDonald Hus, if you are staying there.

Please contact Ronald McDonald Hus or Akademiska barnsjukhuset in advance if you want to borrow these items.



Proton therapy is conducted at Skandionkliniken. This is the only clinic in Sweden that carries out this type of treatment, so everyone who needs proton therapy travels to Uppsala.



- **How is proton therapy at Skandionkliniken done?**

You can read about proton therapy on Skandionkliniken's website

www.skandionkliniken.se/en/treatment-step-by-step/

The website has videos that show how the treatment works, both if the child is and is not sedated during treatment.

- **How long does the treatment take?**

The treatment takes 20–60 minutes, depending on what part of the body is irradiated and how the radiation dose is planned. If the child is to be sedated during treatment, there will be additional time for sedation and recovery, up to two hours.

- **Will my child need to be undressed during the treatment?**

The child needs to be undressed on the body part to be treated.

- **Why does my child need a facemask during treatment?**

It is important that the patient does not move during treatment. The mask holds the child's head still. It is manufactured at your child's regional paediatric oncology centre and sent to Skandionkliniken for the treatment. Children can have their masks decorated if they like.

- **Can I sit with my child during the treatment?**

No, you cannot be with your child in the treatment room during radiation therapy. Healthcare professionals will help the child with everything. They will see and hear your child the entire time on video screens with speakers and can stop the treatment if necessary. While the child is being treated, parents are welcome to wait at the entrance square, Skandionkliniken's waiting room.

- **Can someone see and talk to my child during treatment?**

Yes, the staff can see, hear and talk to your child during treatment via a video screen, speakers and a microphone. But it is important that the child lies still during the treatment, so they should preferably avoid talking.

- **What side effects can my child have after a proton therapy treatment?**

Any possible side effects your child may have depend on what part of the body is irradiated and how the radiation dose is planned. The doctor in charge can answer questions and provide more information about possible side effects.



Accommodation at Ronald McDonald Hus

Many people are offered the opportunity to stay at Ronald McDonald Hus during the treatment period. It is not a hotel, but serves as a home away from home. You do your own shopping, cooking, laundry and other everyday tasks just like at home.



- **Who can stay at Ronald McDonald Hus?**

Many people are offered the opportunity to stay at Ronald McDonald Hus during the treatment period.

The child receiving treatment can stay here with one or more accompanying family members. For specific reasons, no more than five people can stay in each room at Ronald McDonald Hus.

- **Can family and friends visit?**

Yes, you can receive visitors at Ronald McDonald Hus, but you must okay it with the staff at the house first.

- **What does it cost to stay at Ronald McDonald Hus?**

It doesn't cost anything for you and your child to stay at Ronald McDonald Hus during the treatment period, as long as your home region has approved it and thus accepts the cost.

- **Are there staff available at Ronald McDonald Hus?**

Yes, staff are available round-the-clock.

- **What do I need to bring to Ronald McDonald Hus?**

You need to bring your own clothes and other personal belongings. It can also be a good idea to bring something that makes your child feel secure, such as cuddly toys and other playthings.

Bed linens and towels are available to borrow at Ronald McDonald Hus.

Your first breakfast is provided when you and your child arrive, but after that you are responsible for your own expenses and buying your own food as long as you stay in the house.



- **Is there parking next to Ronald McDonald Hus?**

Yes, there are parking spaces for residents at Ronald McDonald Hus, but they cannot be guaranteed to everyone as there are a limited number of spaces.

- **Is there Wi-Fi in the house?**

Yes, there is Wi-Fi for all residents at Ronald McDonald Hus.

- **Are there bicycles to borrow?**

Yes there are a limited number of bicycles to borrow.

- **Can I have my post forwarded to Ronald McDonald Hus?**

Yes, you can have your post forwarded to Ronald McDonald Hus. We recommend that you do so, so you don't miss any important letters or bills while you are staying in Uppsala.



Accommodation at Ronald McDonald Hus

All other care for your child apart from the proton therapy takes place at Akademiska barnsjukhuset's paediatric oncology department. This department is medically responsible during your child's treatment period in Uppsala. This is also where the hospital school and play therapy are located. Your child's regional paediatric oncology centre and the paediatric oncology department in Uppsala make careful preparations before you come.



- **Is paediatric cancer care the same at Akademiska barnsjukhuset as it is at my child's home hospital?**

The routines at Akademiska barnsjukhuset may differ somewhat from those at the hospital where your child is normally treated, but the care itself is always the same.

- **Who will we come in contact with at Akademiska barnsjukhuset during the treatment period?**

You and your child may be in contact with several medical professionals at Akademiska barnsjukhuset during your treatment in Uppsala, such as:

Doctors and caring staff at Akademiska barnsjukhuset and the paediatric oncology department, who are medically responsible during the treatment period in Uppsala.

A contact nurse, who meets with all children who are treated at Skandionkliniken and their families, and who is a complement to other healthcare staff in the paediatric oncology department.

A social welfare officer, who is available for all children and families treated at Skandionkliniken. At the beginning of proton therapy, you will meet for a run-through, and then you will meet whenever you feel the need.

A dietitian, whom all children meet with in the beginning of radiotherapy and then as often as necessary, because it is important for children under treatment to maintain a stable weight throughout the treatment period.

A physiotherapist and an occupational therapist, whom the child meets as needed.

- **How will we get in touch with healthcare staff at Akademiska barnsjukhuset and the paediatric oncology department?**

You will get a list of phone numbers at your first visit at Akademiska barnsjukhuset. There will always be someone to call if you need help or advice.



School and play

At the hospital school

It is important that your child continues to go to school during the treatment period in Uppsala. That is why Akademiska barnsjukhuset has a hospital school, where all children from year one through high school can receive instruction.

- **Should my child bring their own textbooks to the hospital school?**

Yes, it is good if you bring your own textbooks to the hospital school, even if most instructional materials are available at the hospital school. The hospital teacher will also contact your school to plan your instruction as well as possible.

- **Can siblings be taught at the hospital school as well?**

The hospital school is primarily for the children who are ill and being treated in Uppsala. If space is available, siblings can also attend the hospital school. Please contact the hospital school in advance if siblings need instruction during the treatment period.



At play therapy

All children and young people, regardless of age, are welcome to play therapy at Akademiska barnsjukhuset. It is a place where children can spend time with others or have fun on their own. There are activities for all ages in play therapy. This is also where preschool class is held.

- **Do we need to sign up in advance for play therapy?**

No, you do not need to sign up in advance, and siblings are also welcome.

- **Can siblings come along to play therapy?**

Yes siblings are welcome to come along to play therapy.

- **Are there staff who work at play therapy?**

Yes, there are staff on site, but you parents are expected to remain at play therapy with your child.

- **Are preschool class activities held at play therapy?**

Yes, play therapy has activities for children in preschool class, where they do similar things to what children do in their preschool class at home.



About Protonresan

Protonresan

Protonresan is a virtual visit to help prepare children, young people and their families before attending proton radiation treatment in Uppsala. It is designed in collaboration between the Swedish Childhood Cancer Fund, Skandionkliniken, Ronald McDonald Hus and Akademiska barnsjukhuset.

For more information about **Protonresan (your proton journey)**, please speak to your child's doctor or consulting nurse.



Ronald McDonald Hus™
Uppsala

Skandionkliniken



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