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SCT-Outpatient Clinic
St. Anna Children's Hospital
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Translated by young people for young people!

A co-operation between **International Business College Hetzendorf**

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Hi Kids, my name is Celly.

I'm your personal aftercare guide.

I want to tell you all about the SCT-Outpatient Clinic and what to expect after SCT.

Great!!!

You have managed the transplant – your SCT – fantastically well!

Now your new cells have to grow and your body needs to get strong again. The good news is you will be able to live at home now, and you only have to come and see us in our outpatient clinic for check-ups and treatment.

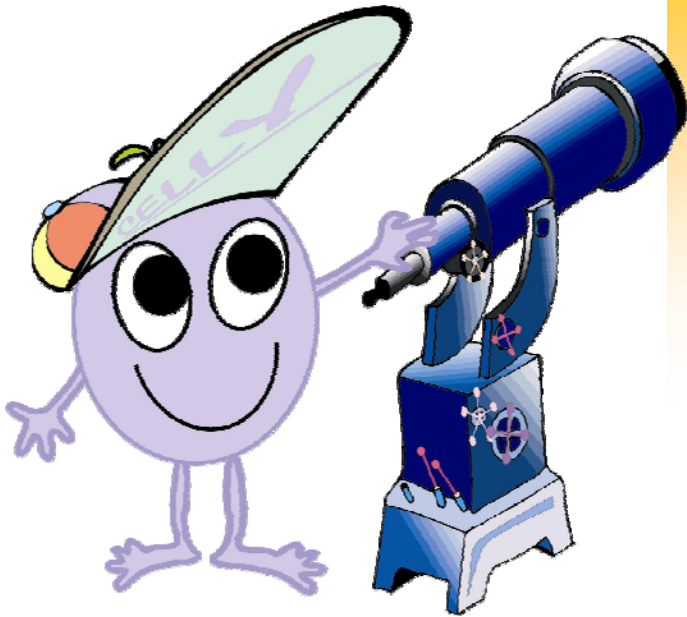
We're sure you have lots of questions about what happens after the SCT, because it is very exciting.

We have tried our best to include everything you need in this booklet.

Whenever you have questions, just ask us and we will be happy to answer them.

By the way: The care after the transplantation is called SCT-after-care.

Read on and find out what SCT-aftercare is all about!



Let me introduce our outpatient-
clinic team. We are all looking
forward to seeing you soon!

Here is a little secret, just
between you and me; I always
call them our Clinic Tigers!



**OA. Dr. Anita
Lawitschka**
Ped. Haemato-oncologist
Head of
SCT-outpatient clinic



**Dr. Natascha
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Ped. Haemato-oncologist



Tina Gertitschke
SCT-outpatient
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Ute Hirtler
Paediatric nurse



Mag. Sarah Rinner
Clinical psychologist



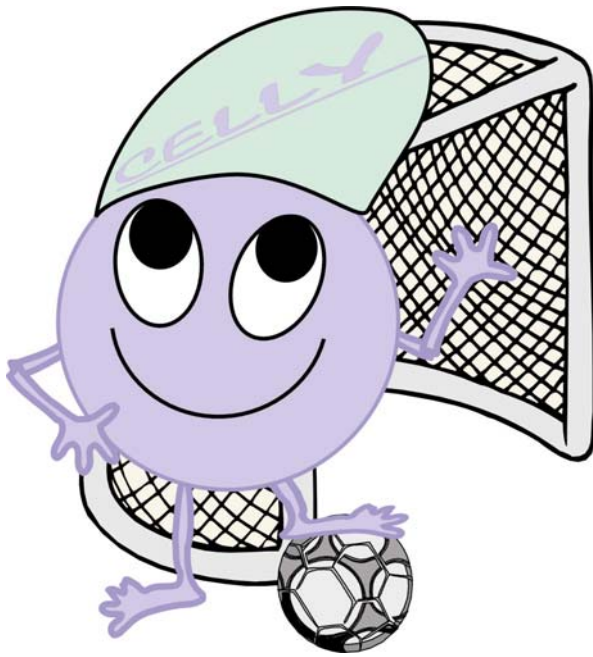
Brigitta Waltl
Social worker



Dr. Ece Güclü
Documentation assistant



Mine Esen
Secretary of the ward



Together we are strong!

Together - you, your family, your clinic team and of course me, Celly – we will make you feel good again.

And now, let me tell you a secret:

Our Clinic Tigers really want to hear all about YOU!

The more you tell them about yourself, the more they can help you.

Attention, Attention!
It is very important that YOU know what's going on!



Don't worry if there is something you don't understand, just ask us; we're really quite friendly and we don't even bite!

Remember it is your body we are talking about!



Being at home is best!

We know that being at home is best. So, we made sure we found a way to treat you so you don't have to stay here all the time. We call this "outpatient treatment".

This means that you will visit hospital quite often but you won't need to stay overnight.



Of course the people of the SCT-team can't be in the clinic all the time. But they want to be there for you when you need them. Check the clinic's opening hours below.

MONDAY TO FRIDAY: 8am to 4pm

>> If necessary we can also arrange a meeting before 8am or after 4pm.



Do you like using your phone? Great!
Please call us if you:

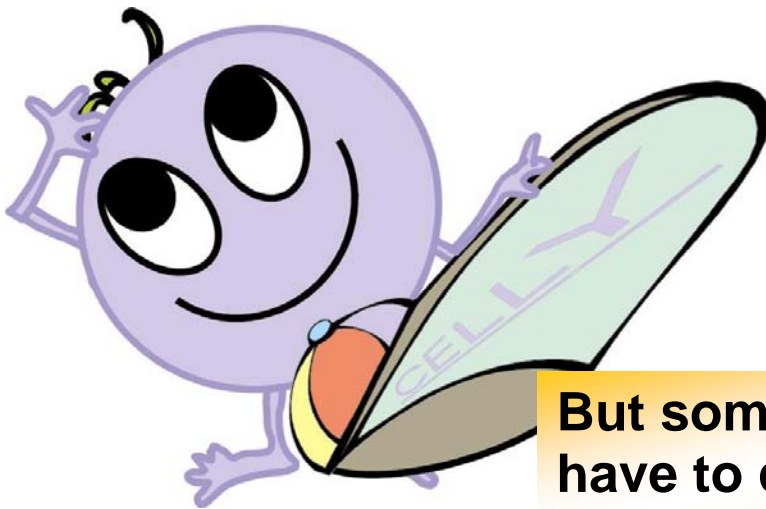
- * have any problems
- * want to ask us something
- * want to come to see us, but don't know when yet.

SCT-Outpatient Clinic:
Telephone: (+43 1) 40 1 70/2900
FAX: (+43 1) 40 1 70/7290

When is it best to call us?

Between 8am and 9am
or between 2pm and 4pm.





But sometimes you may have to call immediately!

Call us, or the senior doctor on duty, straight away on 40170 if you develop any of the following problems:

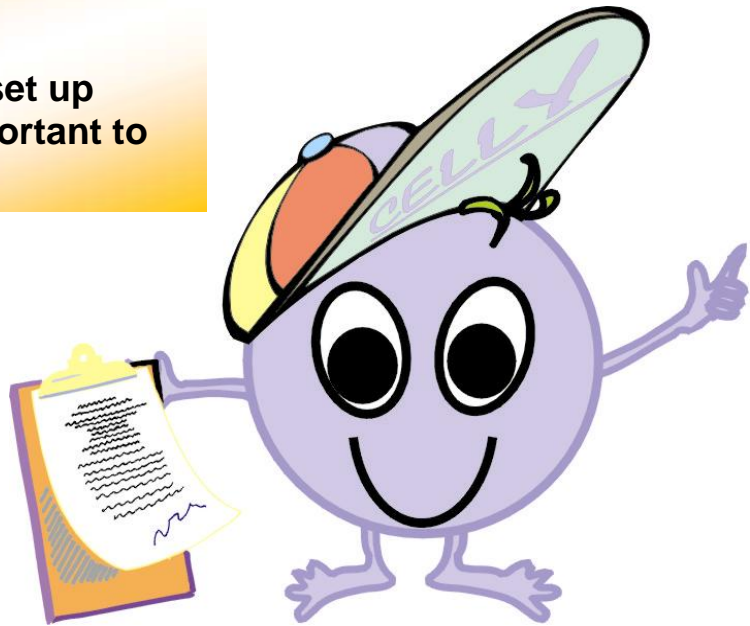


- * high temperature
- * bleeding
- * vomiting
and/or diarrhoea
- * coughing or
breathlessness
- * rash
- * problems with your central line
- * pain
- * accidents, wounds
- * insect stings

Listen!

The Clinic Tigers have set up some rules that are important to follow....

The Clinic Tigers are very strict about those rules, but only because they know how important it is to get you better.



What do you need to do when you come to the clinic?

- * Wear your mask.
- * Walk through the yard.
- * Never walk through the paediatric outpatient clinic.
- * Write your name on the list near our entrance door.
- * Stay in your room while you're in the clinic.

How often do you have to come?

- * 1 to 3 times a week at the beginning; less often later on.



Why do you have to come?

Your Clinic Tigers want to see you, so that they know how you are doing. They want to find out what is wrong and help to make you better. They will:

- * Check your weight.
- * Look after your central line and anything else that's needed
- * Check your blood

They even want to hear your new stem cells growing!





What happens to your body after the transplant?

* In the first few months:

Your new stem cells have settled quite well! Now they have to start their work and produce new blood cells and build up your immune system.



There is more information about these cells in your health dictionary. Why not look it up right now?

If you still don't have enough red blood cells (erythrocytes) or platelets you will get transfusions, like the ones you had on the ward.

In the beginning your new immune cells are not very experienced; it's like they are not quite sure what they are supposed to be doing and there may be not enough of them.

So what do they have to do??

.....That's right! **They have to learn!**

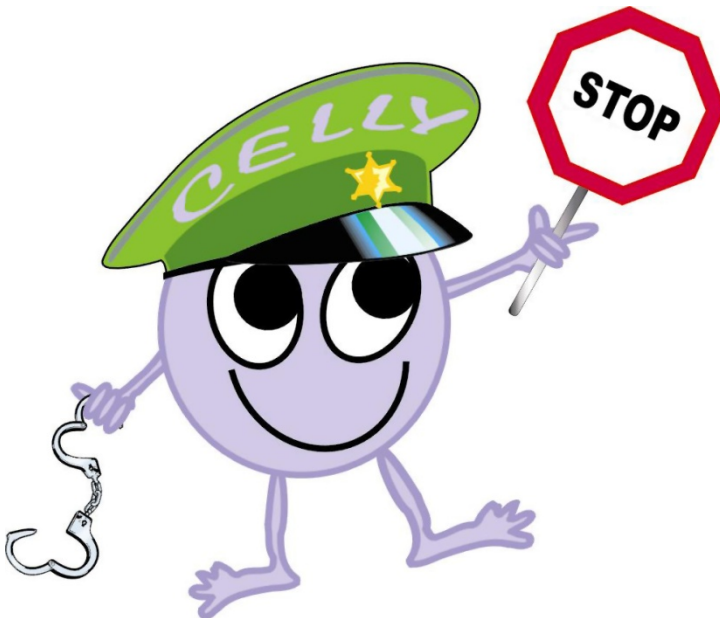
Just like you have to when you go to school. And they have to learn quite a lot too.

Only then are they ready to fight against bacteria, viruses and fungi.

Why is a strong immune system so important?



The white blood cells are a special combat unit. They try to bravely fight any disease that enters the body. But early after SCT you can easily get an infection, because there are not enough cells and they are not fit enough yet. Many infections can be treated but some viruses can become very dangerous for your health. After some time, your immune system grows stronger and better, which means it can help you fight infections better – especially if you are looking after your body!!



Now I will give you some hints on how you can protect yourself.

- * Use your mask when you leave the house.
- * Stay away from areas where there are lots of people.
- * Ask your friends, the Clinic Tigers, if you have questions! They will tell you what sorts of things you can do – and what you should not do.
- * Give your body the best nutrition and exercise.
- * Don't have a big party!

This does not mean that you can't invite any friends round.
You could always invite just a few friends:

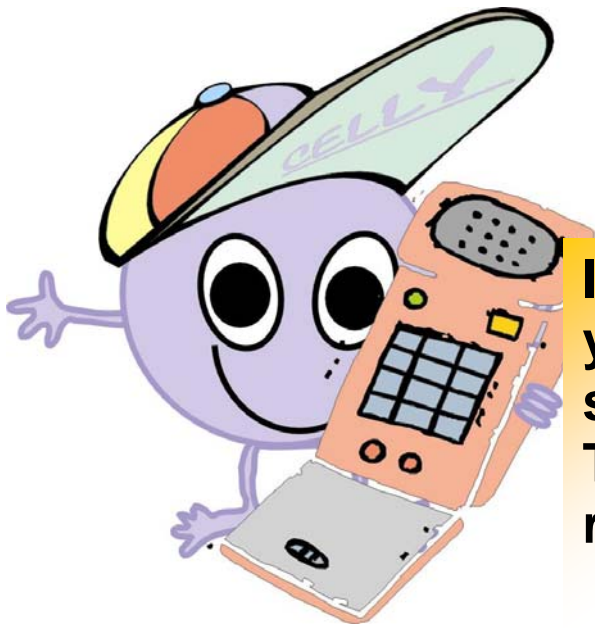
But

- * Your guests must be healthy
- * Your visitors (or you) must wear a mask

A stylized illustration of a red and white mobile phone with a black keypad and a small screen. The phone is set against a purple starburst background.

The fight against infections (and other problems) can be won more easily if we act fast!

Call us straight away if you notice anything unusual, or if someone close to you develops a childhood illness
(for example chicken pox, shingles, measles, rubella, scarlet fever, etc).



If you feel sick, call your Clinic Tigers straight away! They can help you really quickly.



How can they help you?

The Clinic Tigers want to find out what is wrong and help to make you better. May be you will need either medicine to swallow or an infusion via your central line.

We try to make sure that you can do that as an outpatient!

We know that you want to go home as soon as possible.

Don't worry, be happy!

What if you have to stay with us for a while?



You will probably stay right here on our SCT-ward.

But sometimes this might not be possible; for example when we don't have enough space! If this happens, we will organise a room for you on a ward you already know!

Trust us, we won't let you down!

The doctors and nurses on the ward work closely together with us, and you can come to see us anytime if you have a problem (or even if you just fancy a chat!) That's a promise!



What else is going on in your body?

Well, first of all, your body has to get better! Medicine or infections can sometimes jumble up the workings of many parts of your body, such as your kidneys, your intestines, your heart and your muscles. But don't worry; we work hard to make sure everything turns out fine!

Your Clinic Tigers watch your body getting better very closely!

That's why they like to do a big check-up on your body at:

★ + 100

★ + 180

and ★ + 360 days after the transplant (they even call them "checks").

Later on, these big check-ups will only be once a year.

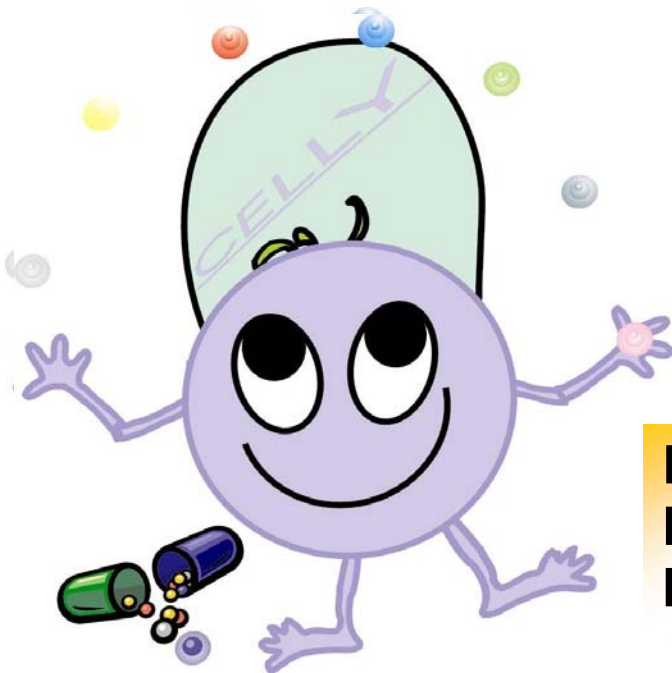
When will you have another bone marrow puncture?

Usually on day + 100 and on day + 360.

As you already know, you will get medicine to help you sleep through it.

That's why it won't hurt! Do you still remember what we call it?

That's right – Little Blue Dream!



How can you help your body?

Take your medicine!

The medicine that you take every day helps the new cells grow and protects you from infections.

If you have any problems with your medicine, just tell us. I'm sure we can solve the problem together.

Or do you have any ideas? 😊



- ★ **Either way, you will need Bactrim (or Eusaprim or Oecotrim ,,):**
This medicine protects your lungs from infections. You need this protection until your body's immune system is working well again. There will also be other medicines that you need to take, but we will tell you about those ourselves because some of them are suitable just for you and are not for everyone.
- ★ **Blood level of your medicine:**
Here we check how much of a particular medicine (in most cases CSA or tacrolimus) is in your blood.

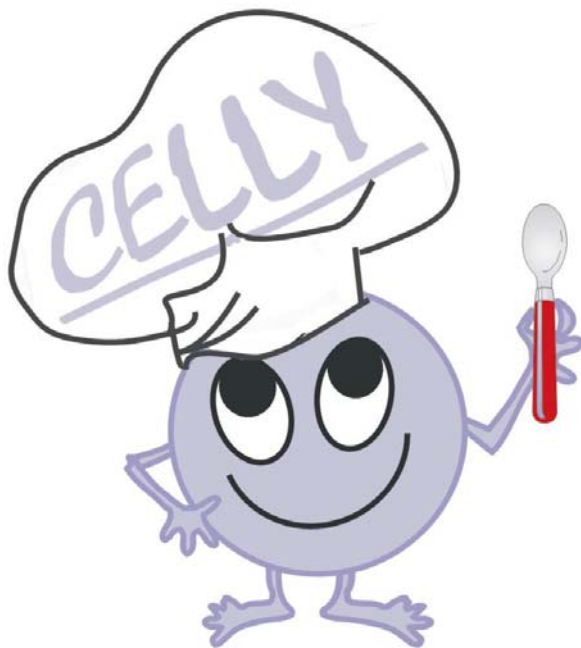
But watch out!

You must take the medicine **after** the blood test in the outpatient clinic! So it is important not to leave your medicine at home. We are counting on you to remember!



Bring your medicine timetable with you!

If you vomit soon (within 30 min) after taking your medicine, I'm afraid you'll have to take it again. But believe me, the little "fighters" in the tablets, capsules and drinks are your friends and they are there to protect you.



Sometimes medicine (especially steroids) can make you feel a bit sad. It's okay to feel any way you want and there are lots of people in our team that you can talk to.

Drink as much as you can, even if you're not thirsty.

Remember!

Food for your body is like petrol for a car.

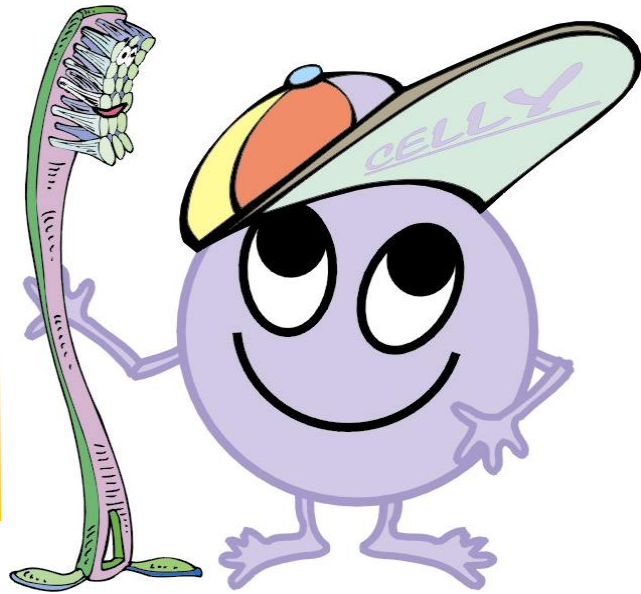
No petrol – No go!

An empty tank will get you nowhere.

A little later in this little booklet, you will find some stories about food and drinks.



Take good care of yourself!



- * Have a shower every day.
- * Put plenty of cream on after having a shower.
- * Brush your teeth and rinse your mouth – this is very important. That way those little goblins in your mouth – bacteria and germs that cause caries – don't stand a chance and cannot harm you.
- * Wash your hands a lot. Remind your family of this as well!

Be alert, like a detective!

Important:

Your enemies lurk in many places. Avoid them!

Stay away from these things:

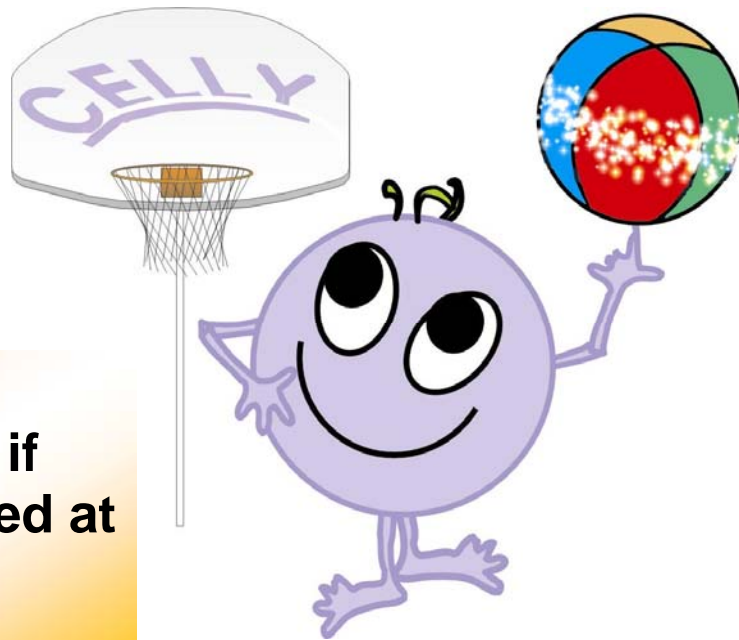
- * Earth, sand, leaves and building sites; here you will find fungi, which can make you sick.
- * Lots of people, for example in schools, kindergartens, buses or trains. It could be that some of them have an infection. We don't want you to catch anything!

**Do you know other places where many people come together?
Think about it!**

- * The zoo, circus, stables
- * Public swimming pool

Before you go to any of these places, you have to wait until your immune system is better again. We will tell you straight away when that is. Again we are here to answer your questions and give you advice!

Do a lot of exercise, even if you are still tired at the beginning!



Why?

Exercise is important, because your body needs to get going fast. When you are more active, your metabolism increases and starts to build muscle tissue.

But watch out: if your platelets are still low, you shouldn't jump or fall over.

The best way is to start slowly. Do a little bit more each time so that your body gets used to it.

Even if you feel like it's a struggle don't be put off

Tip

Our Physiotherapists always have good ideas and I'm sure they will find the greatest training programme for you!

Travelling to other countries is great – but please, not now!



You don't have to worry.
To put off something, doesn't mean that it will never happen!
When your immune system is OK again, you can head off.

There are no problems with stays in the Rehab-Clinics in:

- * Tannheim
- * Katharinenhöhe



Are you allowed to be together with your animal friends?

You can be with your animal friends if they already lived with you before your illness.
But they should be vaccinated and de-wormed.
Only birds cannot be with you in the same room.

You should give this a miss, just for a while:

- * Cuddling your pet too close.
- * Letting them sleep on your bed.
- * Cleaning your pet's litter tray.





What is GvHD?

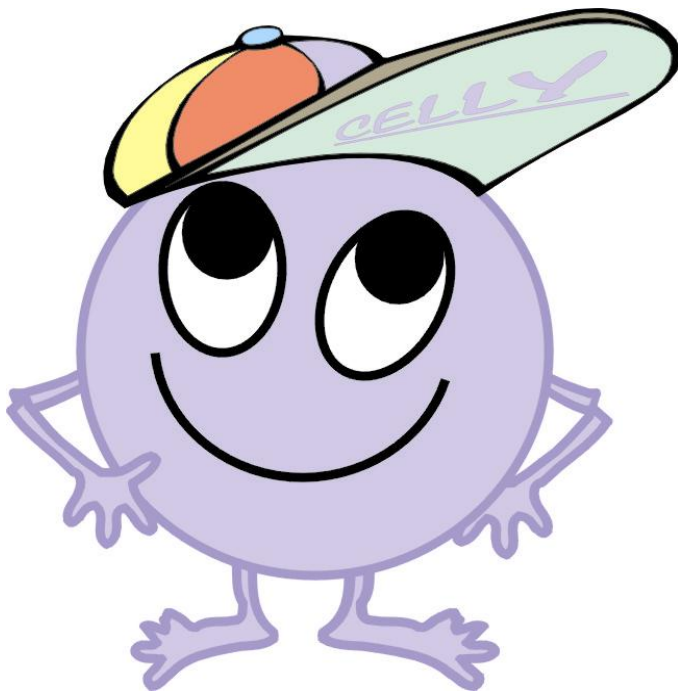
GvHD is a name for “Graft versus Host Disease”

Your new immune cells realize that they are in a new body. Sometimes they don't recognise your body as their new home and they get mad and protest. How do they protest? They cause inflammations.

- * Mostly these are rashes or eye inflammations.
- * Sometimes they are inflammations of the mouth or intestine.
- * Very rarely there will also be inflammations on other parts of your body.

What is a chronic GvHD?

We call it chronic, if GvHD is present after day + 100.



What can we do about it?

Your Clinic Tigers give you mainly steroids and other medicine. This tires the mad lymphocytes so they can calm down and learn.

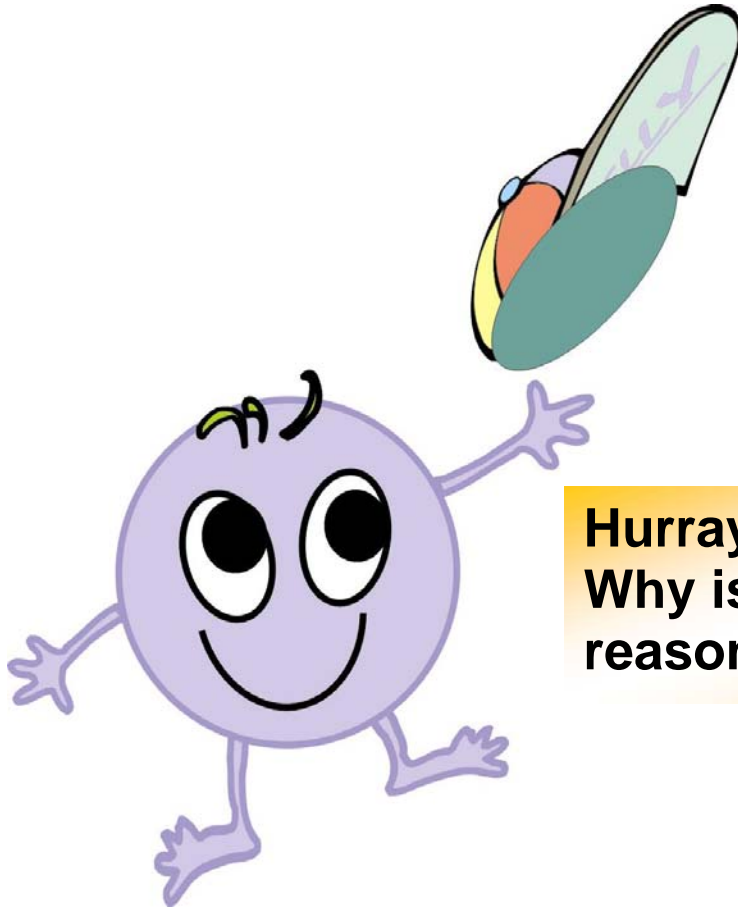


How does this affect you?

- * At the beginning you come to the outpatient clinic more often.
- * The risk of getting infections is higher – so watch out!

But – For every negative there is a positive!

If you had a transplant because of a leukaemia, the GvHD gives you additional protection against getting this disease again.



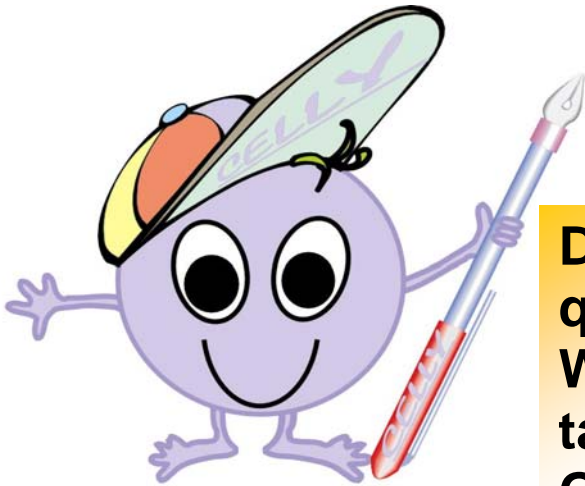
**Hurray, day +360!!
Why is this a good
reason to celebrate?**

- * **Your body is almost completely healthy again.**
Now, you will normally only need to come every 2 to 3 months for a blood test. This is nothing more than a little prick on your finger. **Though your Clinic Tigers would still really like to see you once or twice a year too!**

Uh-oh, I almost forgot something really important!

Another step to get well after a transplant is getting vaccinated again! This is important, so your new immune system can learn a lot and become very clever.

Even if you become as strong as an ox and as big as a bear, your SCT team would be really happy to hear from you. Your Clinic Tigers will still be there for you! Just call if you have any questions or problems.



Do you still have questions or ideas? Write them down and talk to your SCT - Outpatient Team about them!
