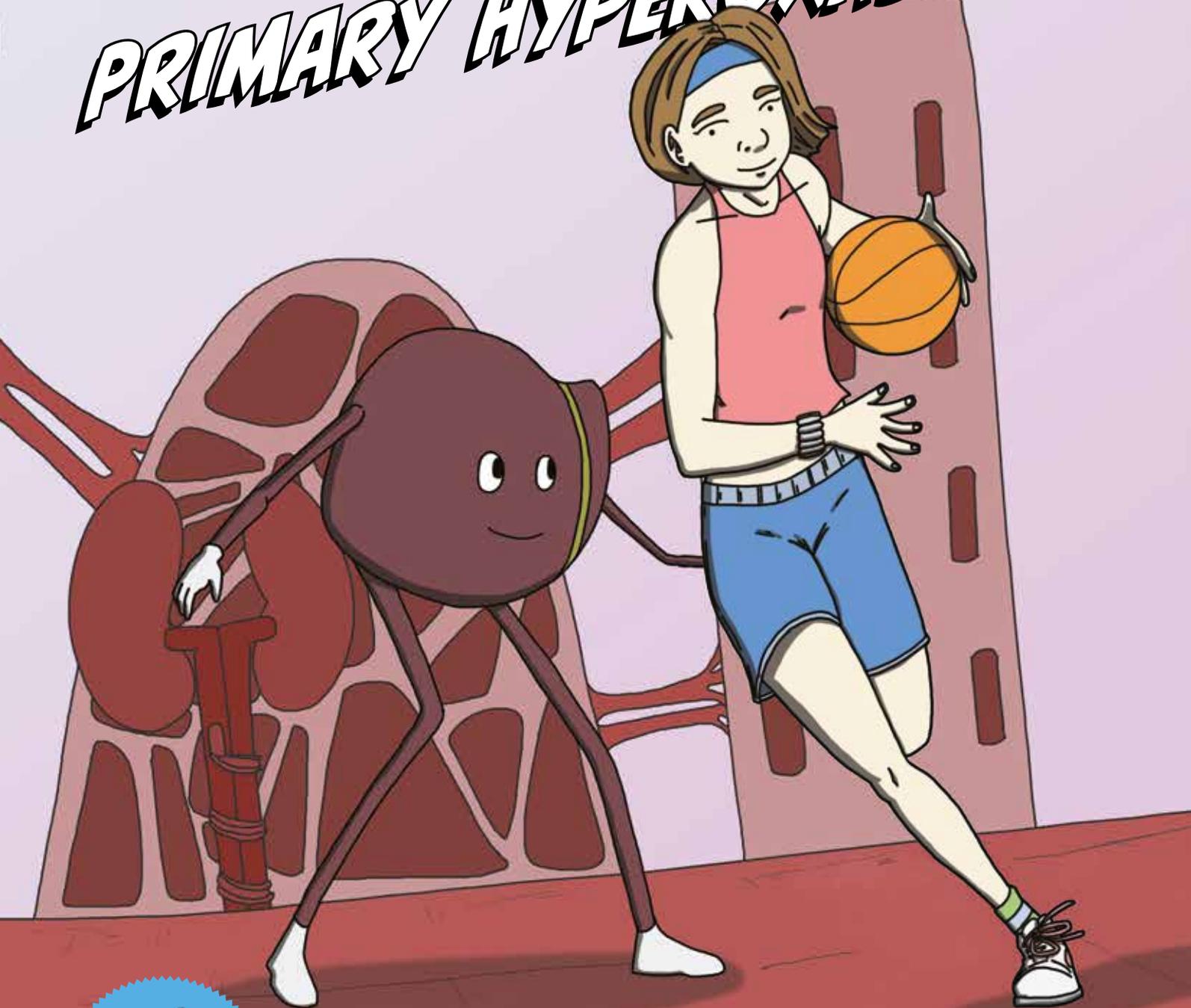


MY LIFE WITH PRIMARY HYPEROXALURIA



IMPRINT

idea:

Dr. Cristina Martin-Higueras &
Prof. Dr. Bernd Hoppe,
PH&HP team

Concept, design and illustration:
Gipfelgold Werbeagentur GmbH,
Bonn, Germany
www.gipfelgold.de

1st Edition 2021

Copyright: PH&HP team



HELLO

My name is Noemi.
I am 14 years old.

When I think of my childhood,
I remember mostly doctors and
hospitals. Sure, sometimes my life
was normal too, but it was always
influenced by my disease
Primary Hyperoxaluria (PH).

But let me start from the beginning:

As a baby, I cried a lot and my parents often felt helpless. Pediatricians reassured them and said babies cry a lot and they shouldn't worry. But when I turned three and still cried all the time, my mother became angry.

"How can nothing be wrong?" she said to the doctor.

"We have to go to a hospital. Because the crying must have a reason. I think my child is in pain."

And then it all started:

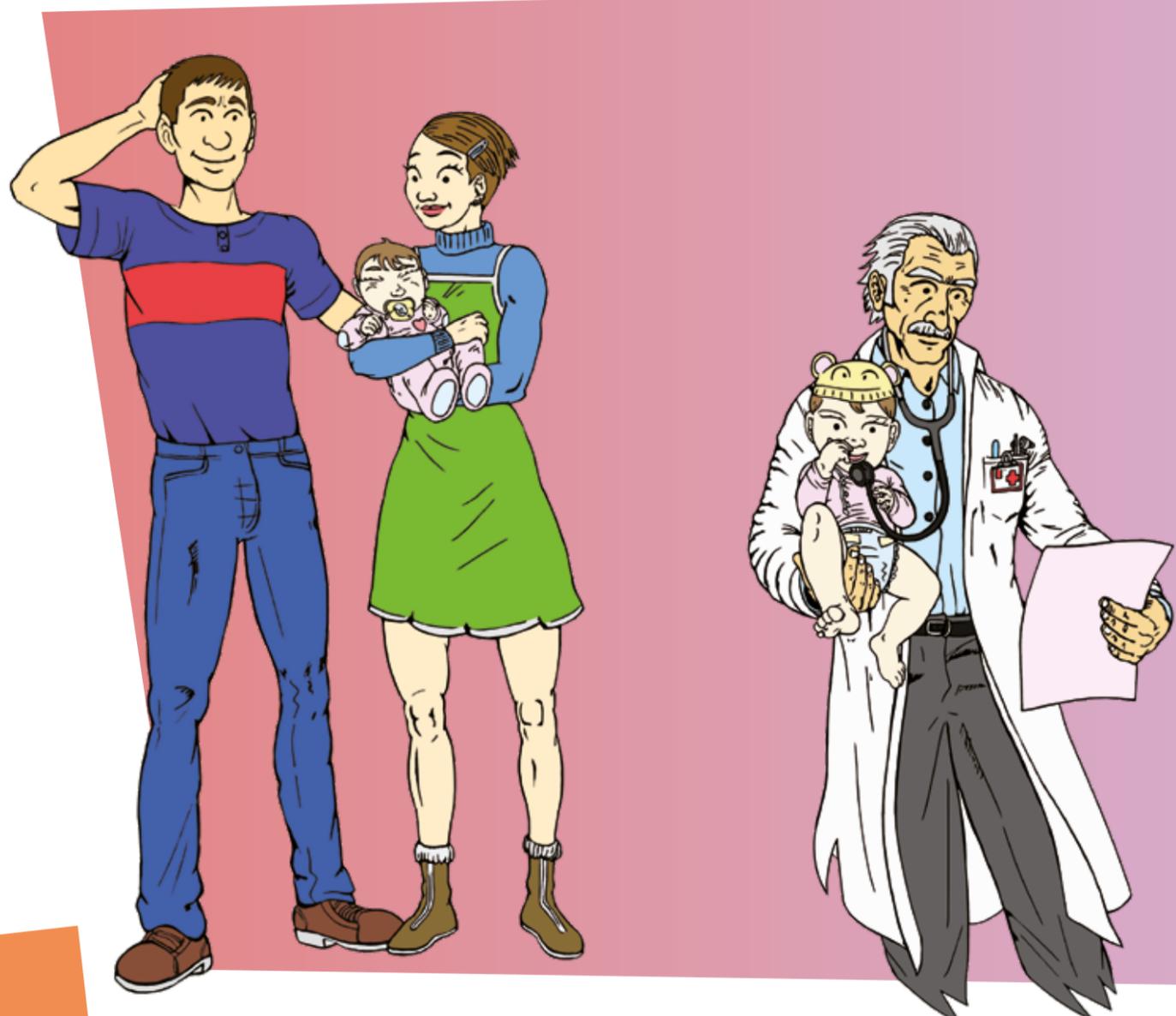
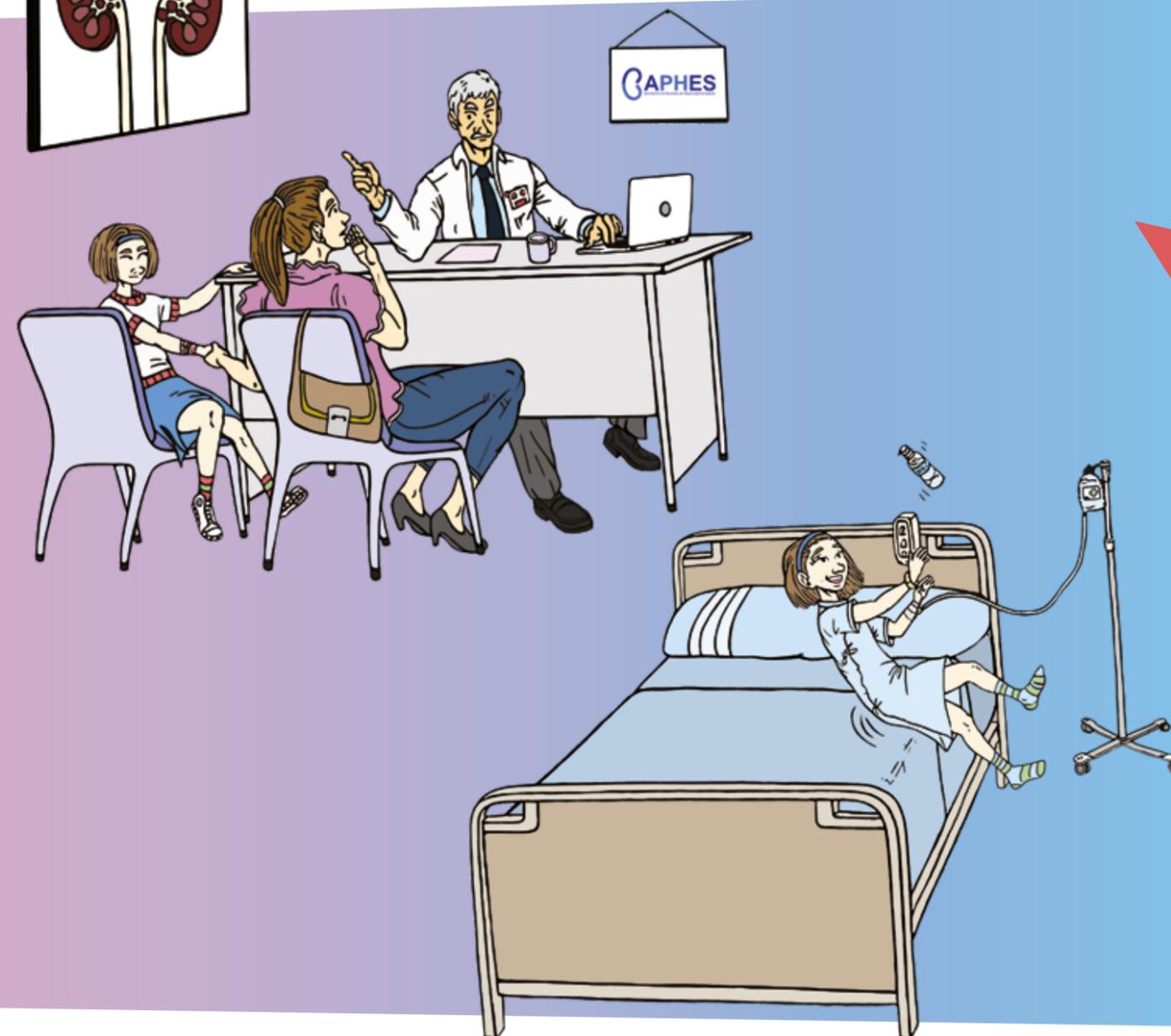
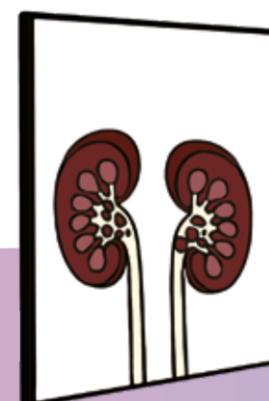
I was thoroughly examined in a hospital. First, an infection of the urinary tract was diagnosed, one ultrasound followed the next, urine was analyzed and a genetic test was performed. I remember doctors and more doctors. I was too little to understand what was going on. I only knew that I was sick and the doctors wanted to help me and gave me many medications. From citrate syrup to vitamin B6 to tablets for my blood pressure.

The genetic test finally gave information:

the doctors diagnosed **Primary Hyperoxaluria Type 1**. I couldn't even really pronounce it, so how could I imagine anything about it? But I could tell from the reaction of the doctors and my parents that my disease was dangerous.

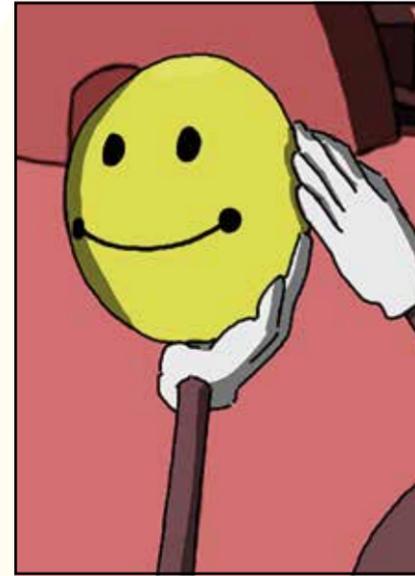
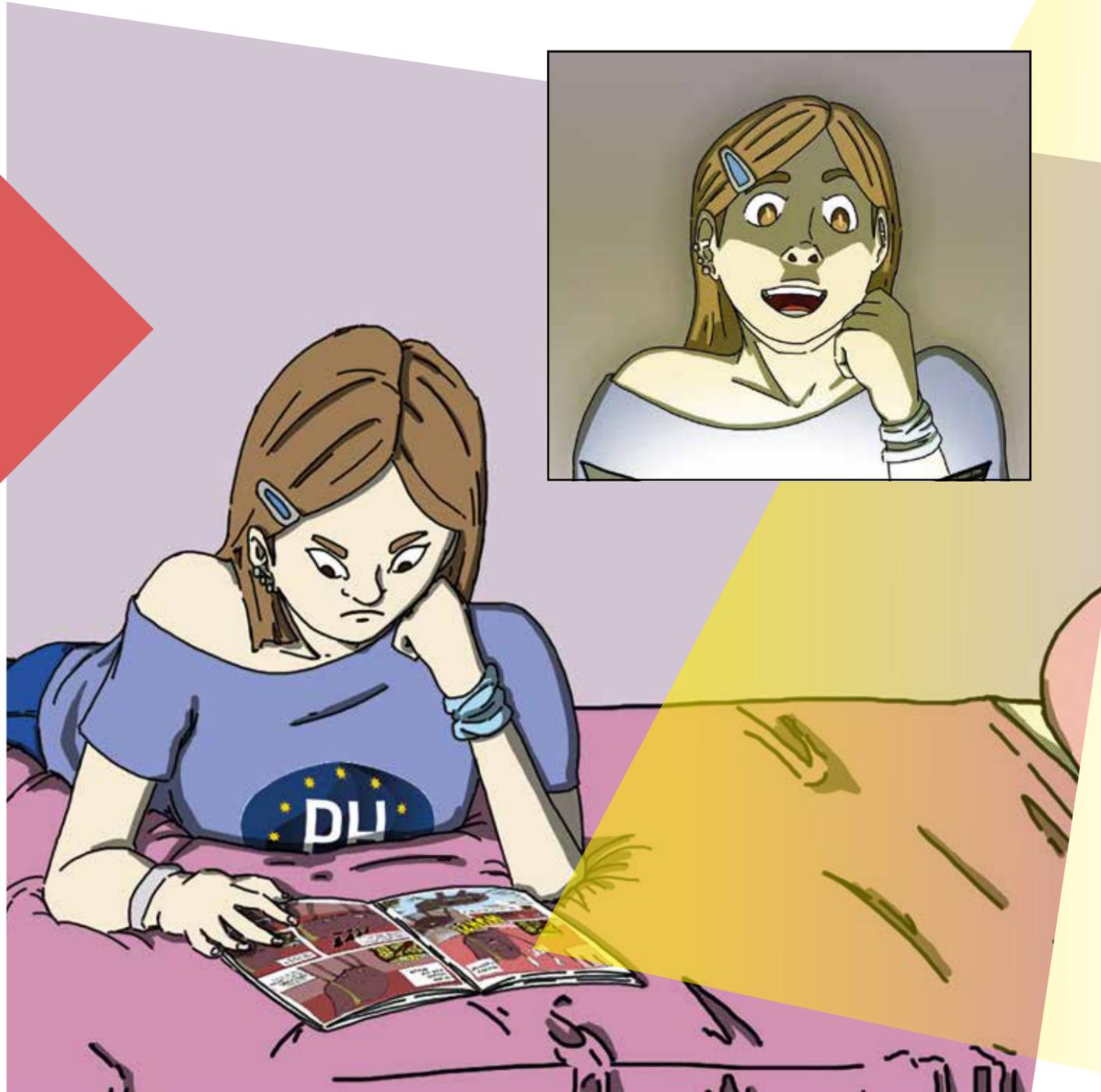
Now I had to take even more medication. I also had to drink a lot every day. I had to get used to that. Unfortunately, I also had pain that went up and down in my abdomen starting in my right kidney. They gave me painkillers to make me feel better.

Again and again over the years, my parents took me to the emergency room and I often missed school because I was too sick to leave my bed.

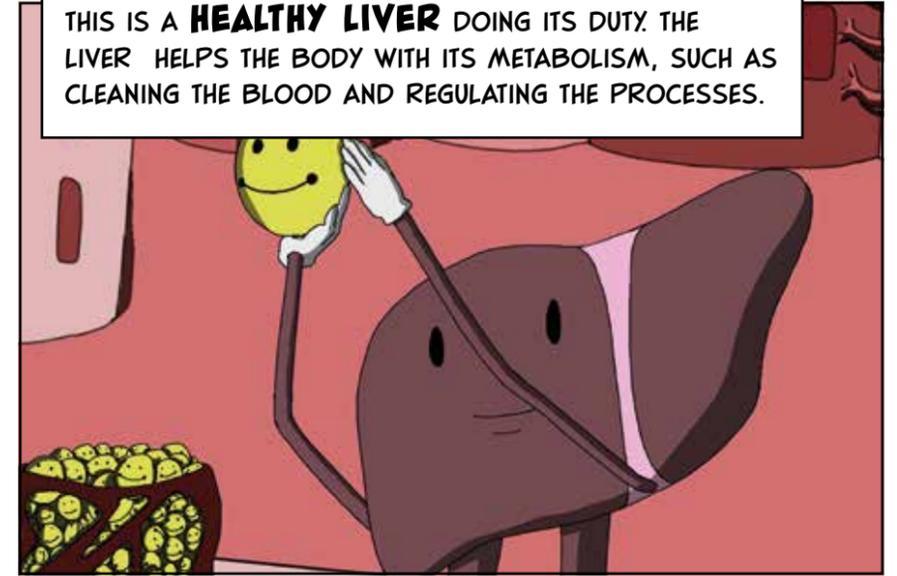


I grew up and wanted to have a normal life. But constantly my mother reminded me to drink enough. And while my friends went to slumber parties, I sat alone in my room.

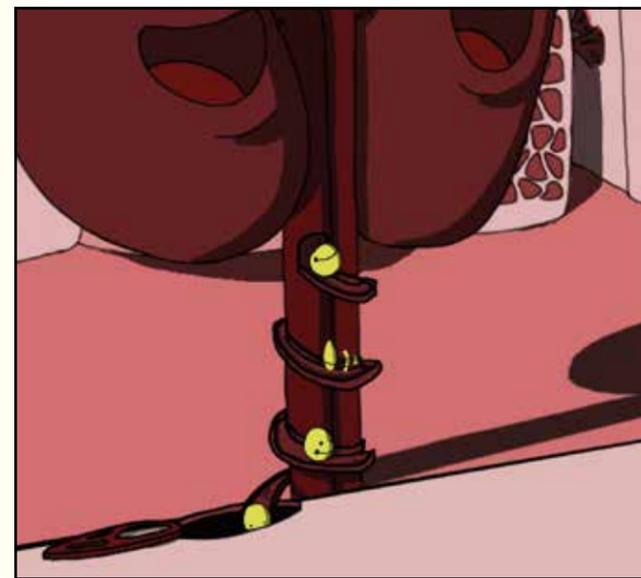
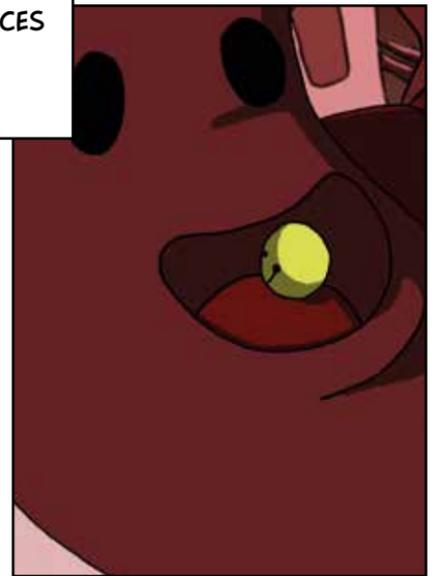
I wasn't allowed to sleep over at other people's houses because of all the medication. I hated that everything was different with me than with my school friends. I felt like an alien. What was going on in my body?"



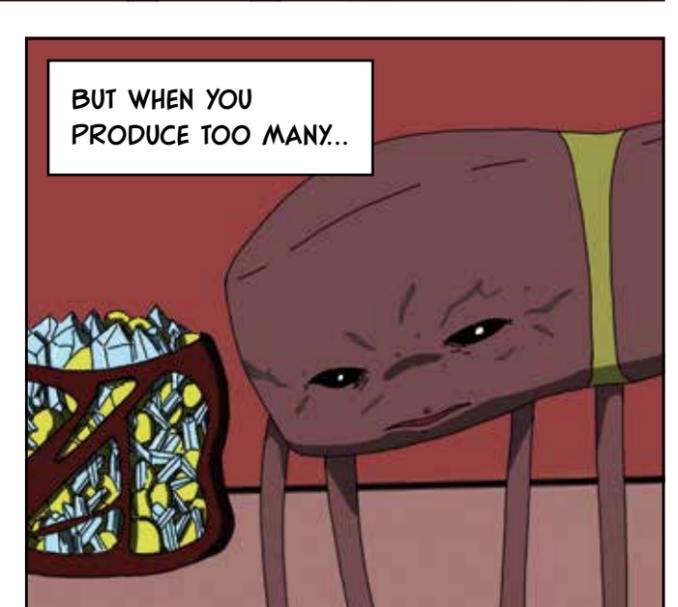
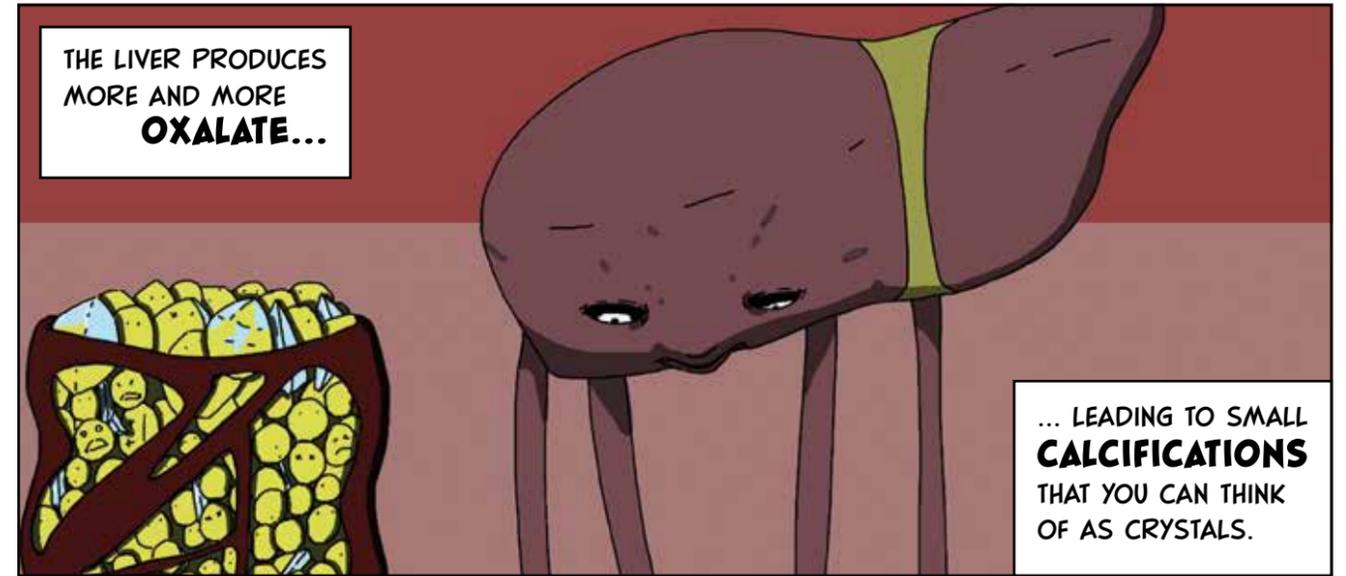
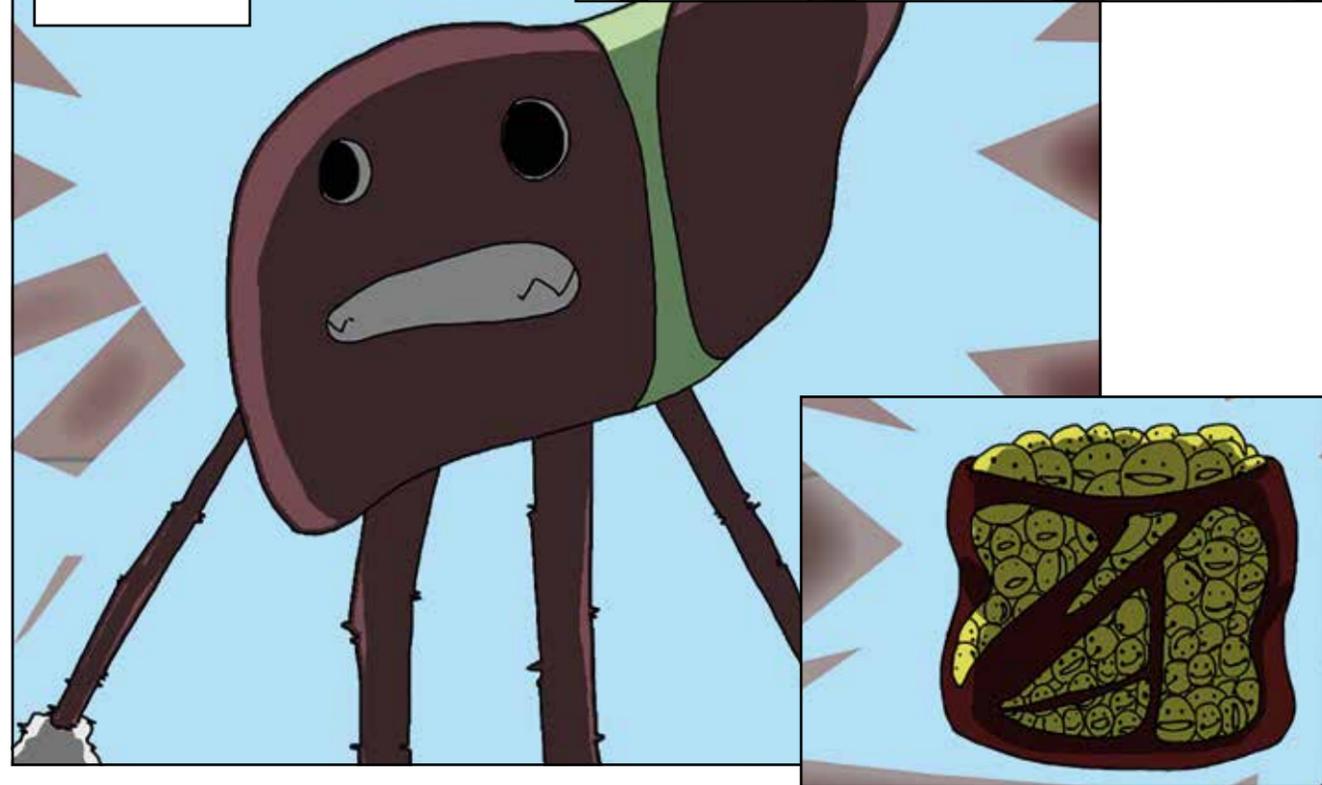
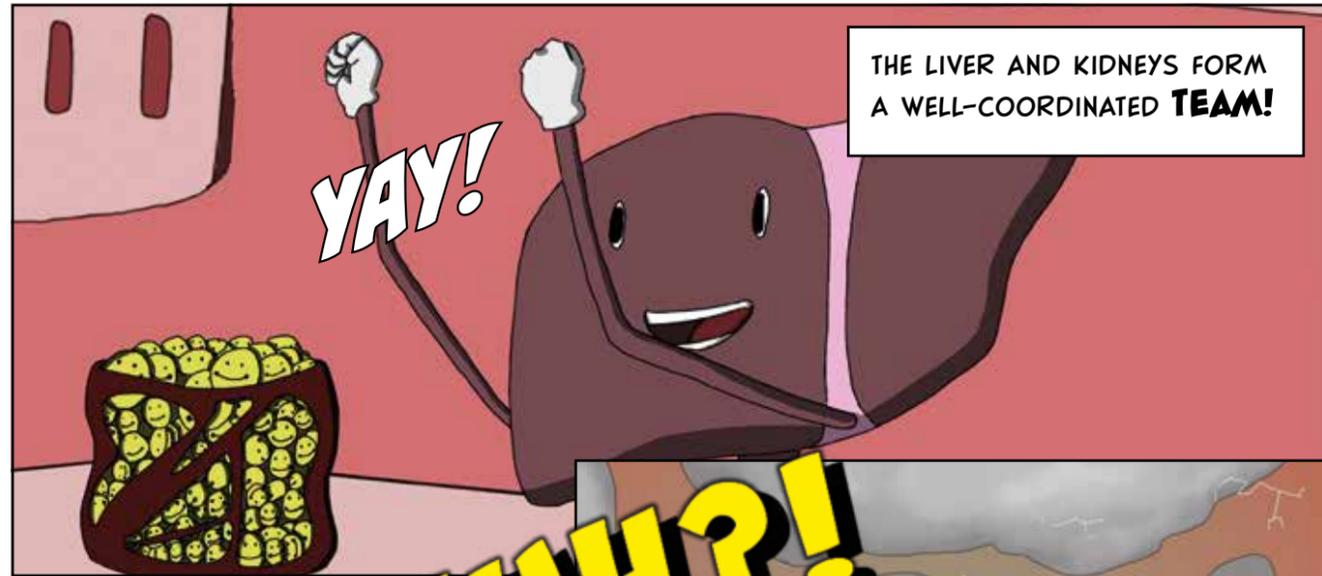
THIS IS A **HEALTHY LIVER** DOING ITS DUTY. THE LIVER HELPS THE BODY WITH ITS METABOLISM, SUCH AS CLEANING THE BLOOD AND REGULATING THE PROCESSES.



THE LIVER PASSES SUBSTANCES THAT THE BODY NO LONGER NEEDS TO THE KIDNEYS.

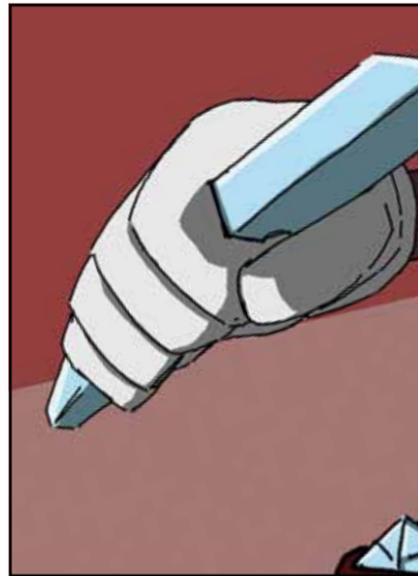


THE KIDNEYS GET RID OF THESE SUBSTANCES IN THE URINE.





REGARDLESS
OF THE CONSEQUENCES...

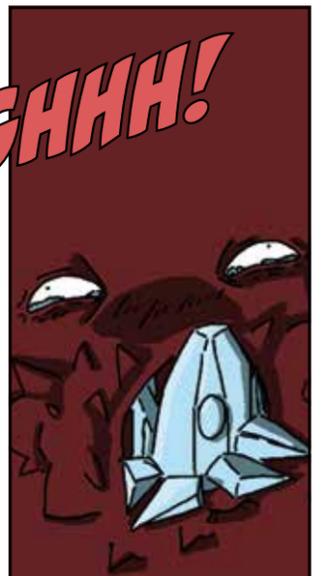
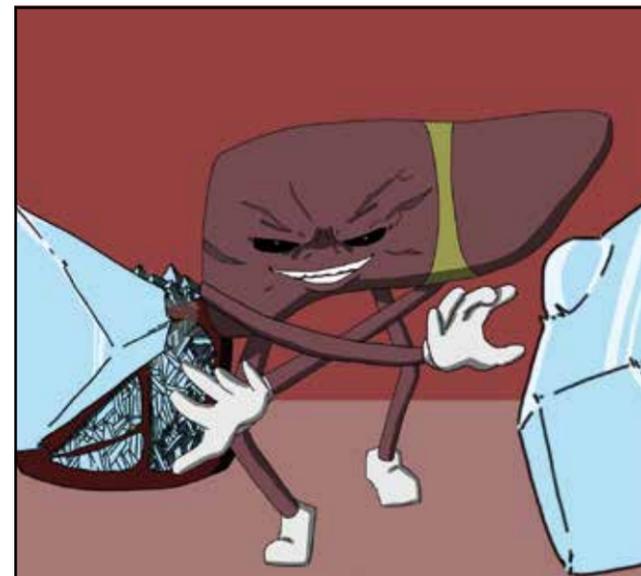


WITH THAT
VOLUME IT
WORKS....

UNFORTUNATELY, AS THE DISEASE
PROGRESSES, **MORE AND MORE**
OXALATES WILL BE DEPOSITED IN THE BODY.



... IT PASSES
THE HARMFUL
OXALATES TO
THE KIDNEYS.

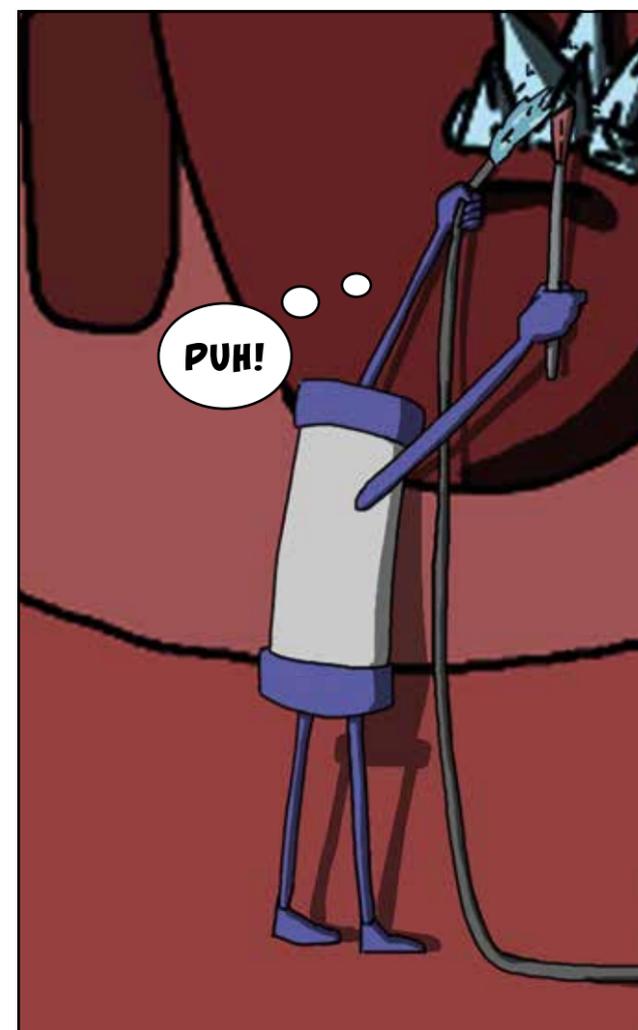
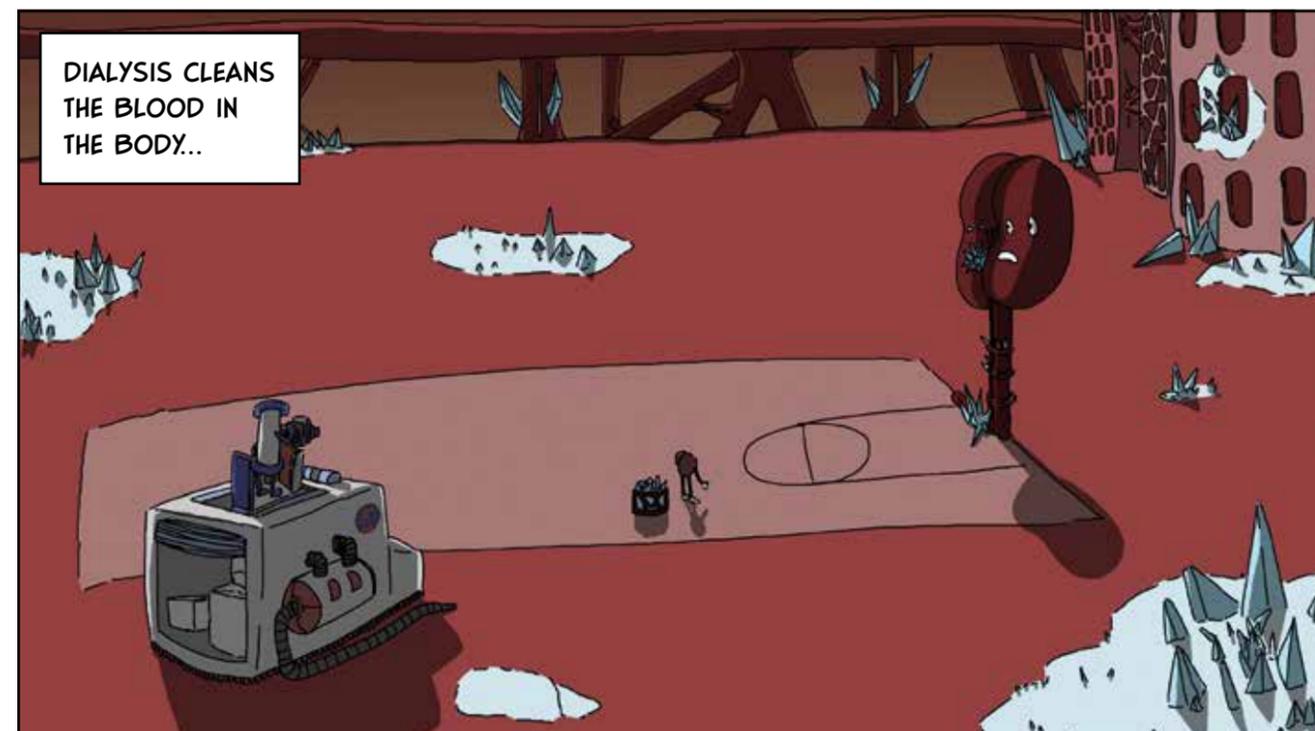
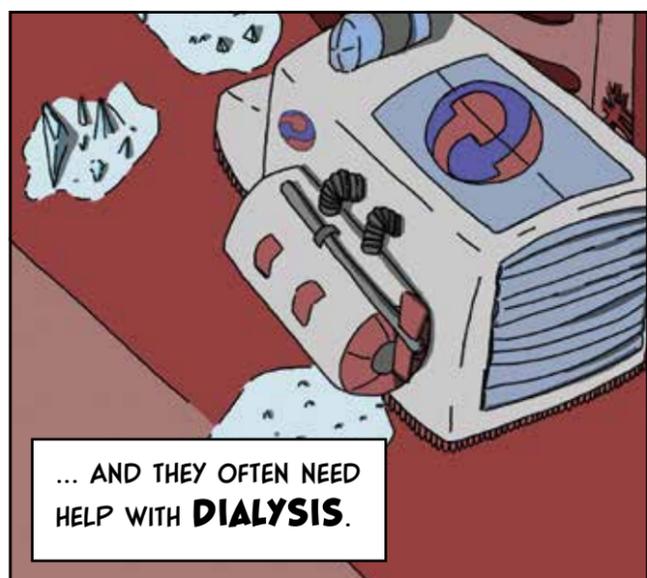
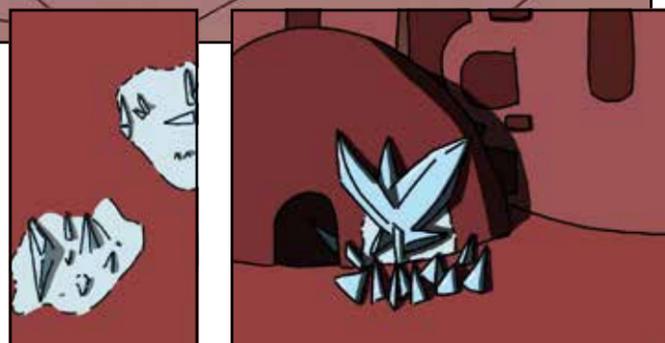
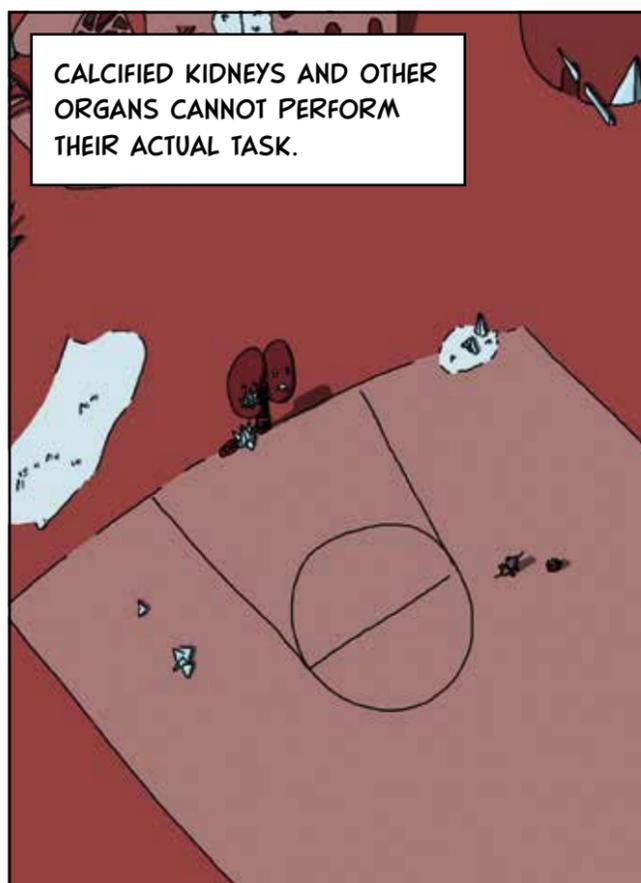
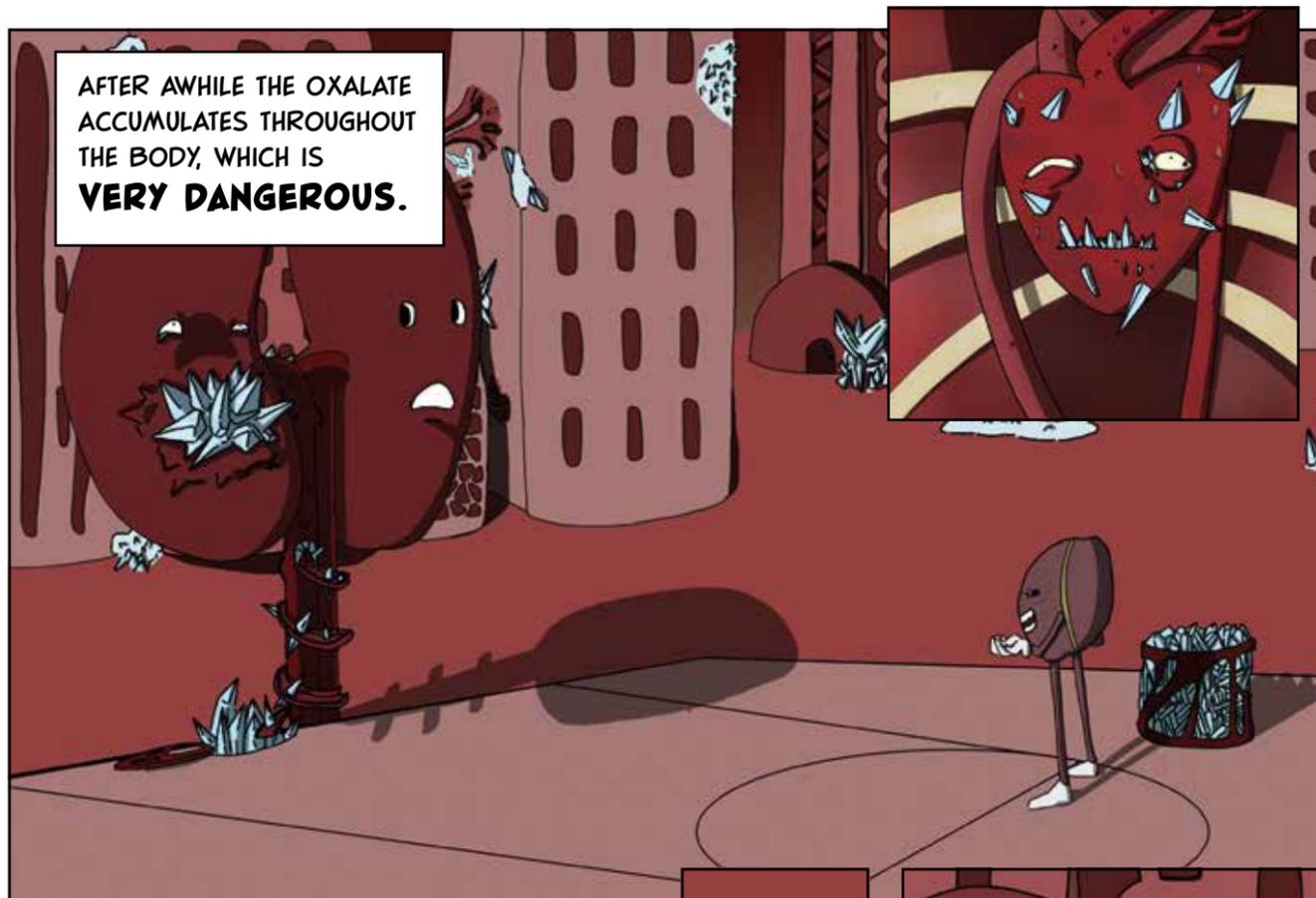


THE KIDNEYS NEED A LOT
OF WATER TO BE ABLE
TO EXCRETE THE BULKY
OXALATES.

IT NEEDS AT LEAST
2 TO 3
LITERS OF WATER.

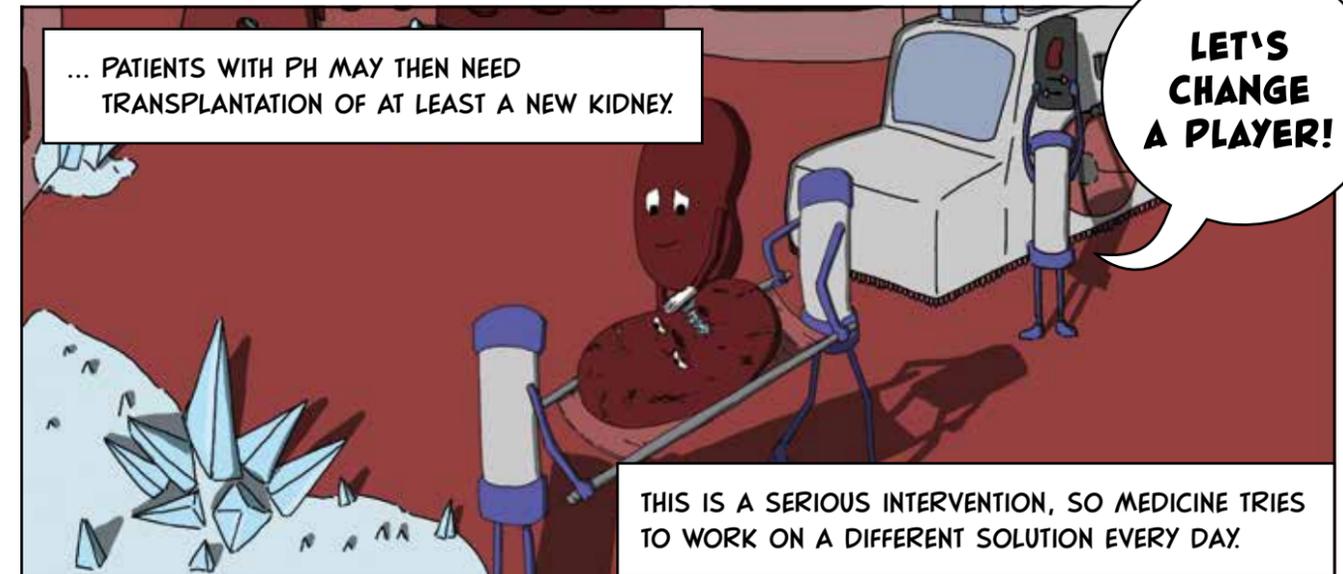
FINALLY THIS CREATES
PAINFUL DEPOSITS...

... WHICH THE KIDNEY CANNOT ELIMINATE
ANY LONGER WITHOUT HELP.





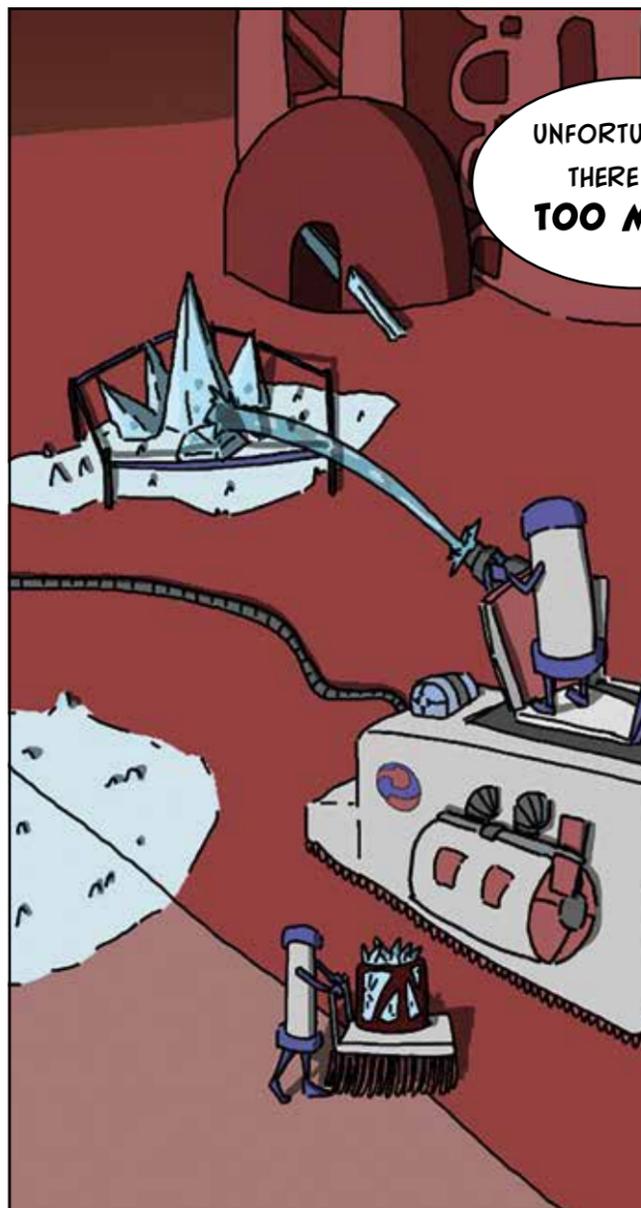
DIALYSIS LASTS MANY HOURS AND TAKES PLACE SEVERAL TIMES A WEEK, SO YOU NEED A LOT OF PATIENCE!



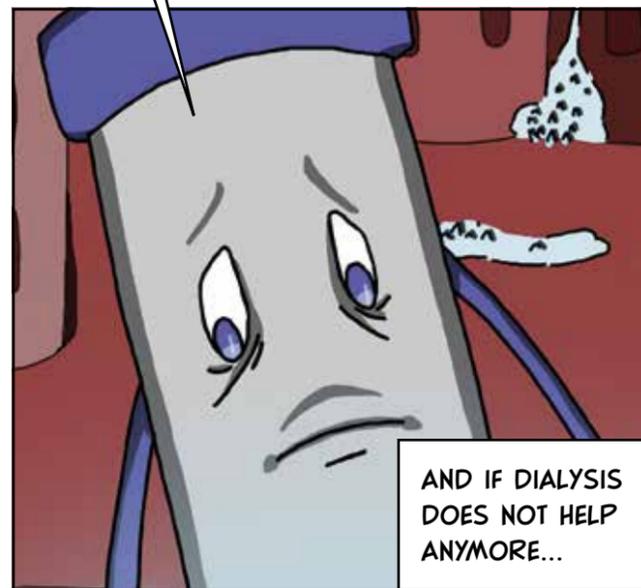
... PATIENTS WITH PH MAY THEN NEED TRANSPLANTATION OF AT LEAST A NEW KIDNEY.

LET'S CHANGE A PLAYER!

THIS IS A SERIOUS INTERVENTION, SO MEDICINE TRIES TO WORK ON A DIFFERENT SOLUTION EVERY DAY.



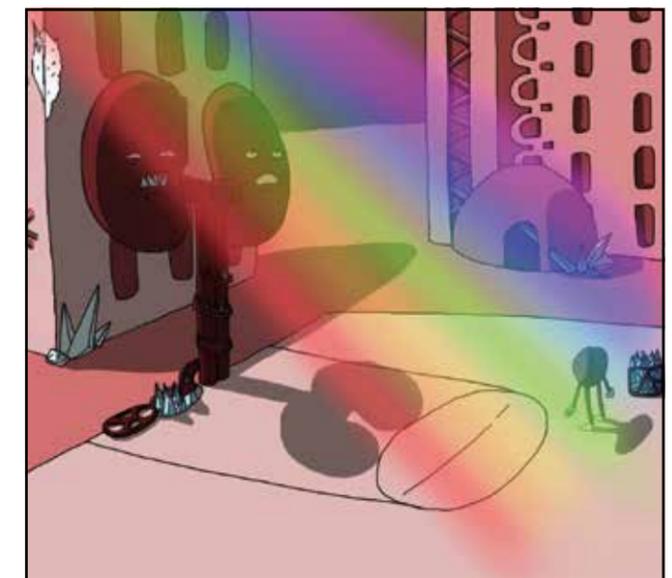
UNFORTUNATELY, THERE ARE **TOO MANY!**



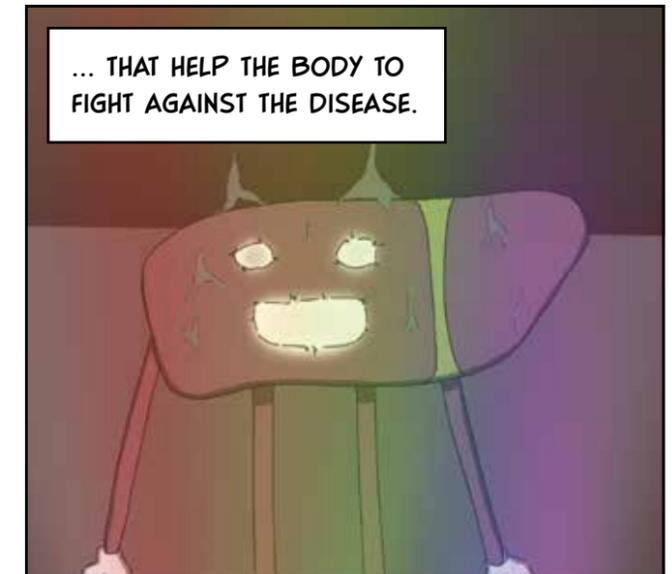
AND IF DIALYSIS DOES NOT HELP ANYMORE...

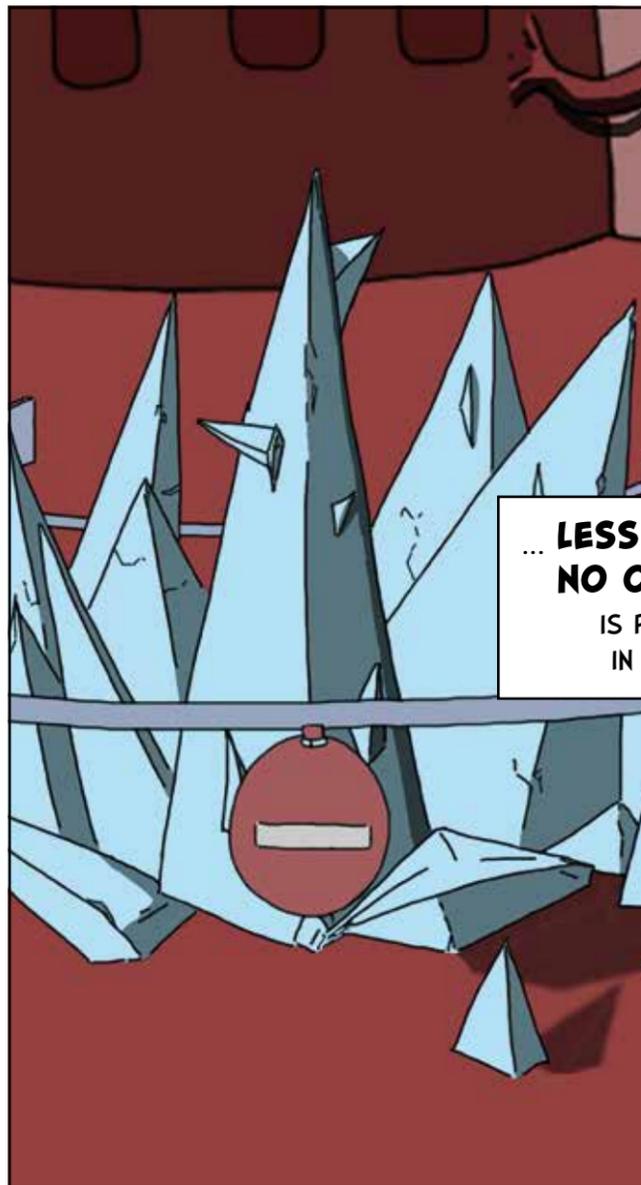
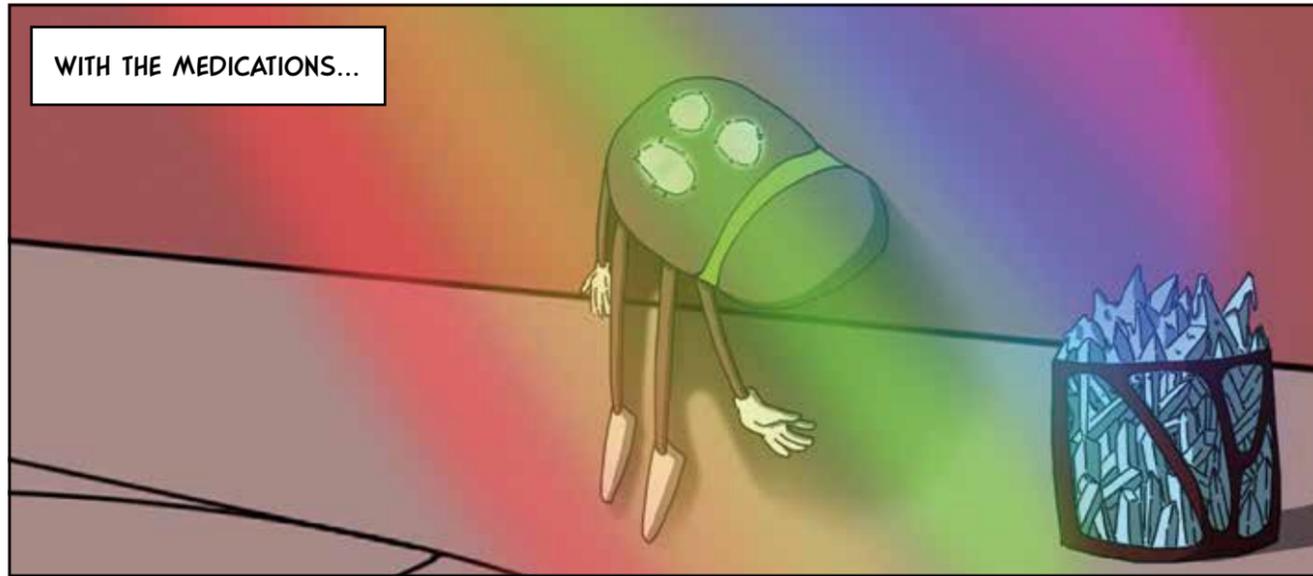


THEY ARE DEVELOPING **DRUGS...**

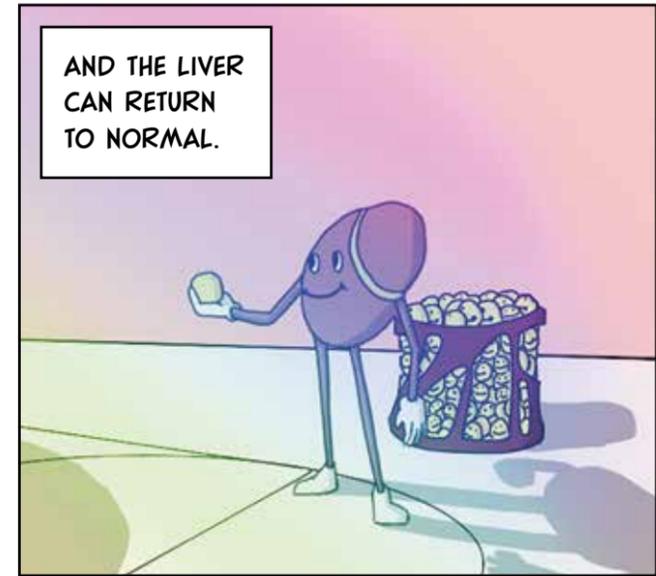
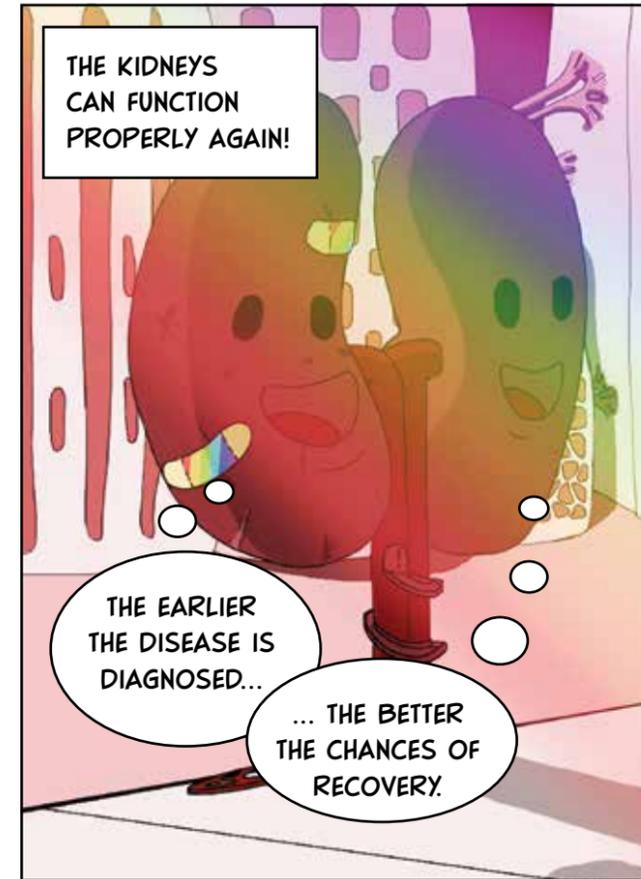
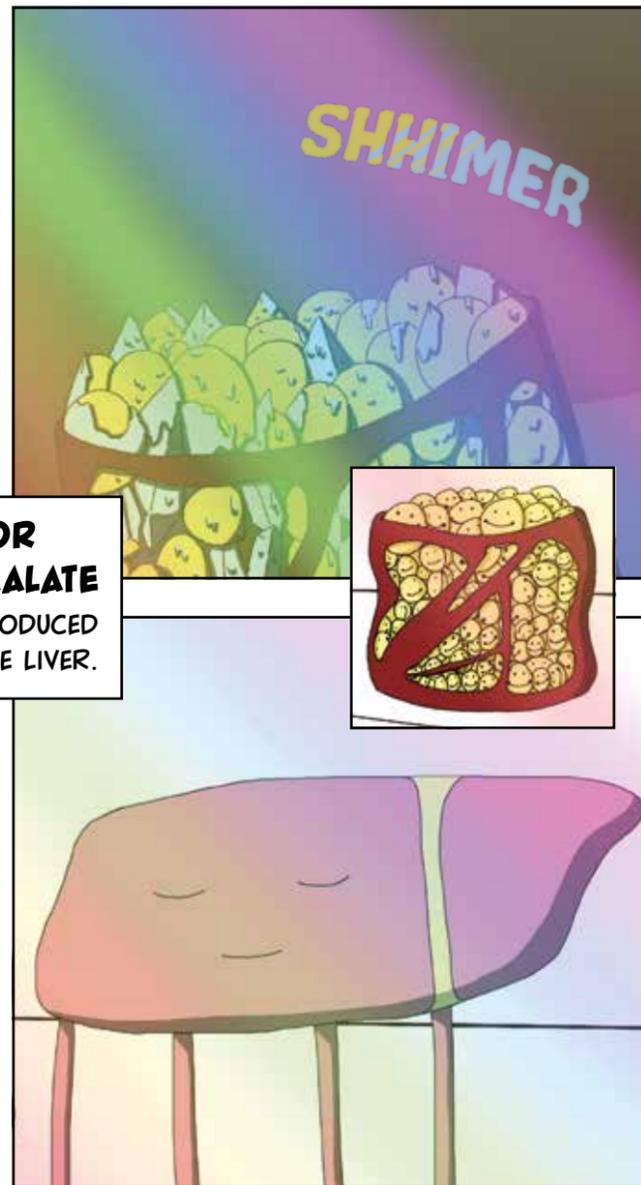


... THAT HELP THE BODY TO FIGHT AGAINST THE DISEASE.

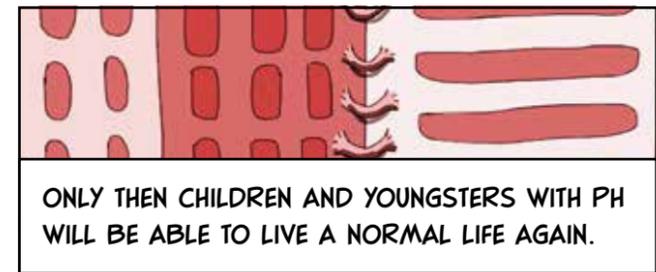




... **LESS OR NO OXALATE** IS PRODUCED IN THE LIVER.



AND THE LIVER CAN RETURN TO NORMAL.



ONLY THEN CHILDREN AND YOUNGSTERS WITH PH WILL BE ABLE TO LIVE A NORMAL LIFE AGAIN.



- END -

Today I am 14 years old and there are pharmaceutical companies that are developing new drugs. I have even participated in a clinical trial myself. The doctors have developed a drug that blocks the production of oxalate in the liver.

But the medical professionals are also working on new drugs that offer further solutions for the treatment of PH.

Of course, I hope that these drugs can help me. But I wish above all PH in children is diagnosed much earlier in the future, so that no one has to suffer as long as I did."



