



NF HERO COMICS

UNDERSTANDING NF2-SWN

MY NAME
IS BILLY AND I
HAVE NF2-RELATED
SCHWANNOMATOSIS, OR
NF2-SWN, A GENETIC
CONDITION THAT USED
TO BE CALLED
NEUROFIBROMATOSIS
TYPE 2.

THIS IS
MY STORY.



UNDERSTANDING NF2-SWN

CALIFORNIA.
PRESENT.

MY NAME IS
BILLY, AND I'M A
FIRST-GENERATION
IMMIGRANT.

I'M ALSO
A MEDICAL
STUDENT.

AND A
PATIENT.

CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH

1995.
AGE 1

I WAS JUST A BABY
WHEN MY FAMILY
IMMIGRATED FROM
VIETNAM.

BECAUSE OF MY
FATHER'S MILITARY
SERVICE,

HE WAS ABLE
TO BRING MY
MOTHER AND ME
TO CALIFORNIA.

THEY WORKED AS
TEACHERS IN SAN DIEGO.
IT WAS SUNNY, HAPPY,
BEAUTIFUL.

AGE 6

WHEN I WAS SIX,
MY PARENTS TOOK
ME FOR A ROUTINE
EYE EXAM.

SOMETHING
HERE IS... NOT
RIGHT.

AT THAT MOMENT,
EVERYTHING CHANGED.

AGE 7

AFTER A YEAR OF GOING FROM DOCTOR TO DOCTOR, I FINALLY HAD AN MRI.

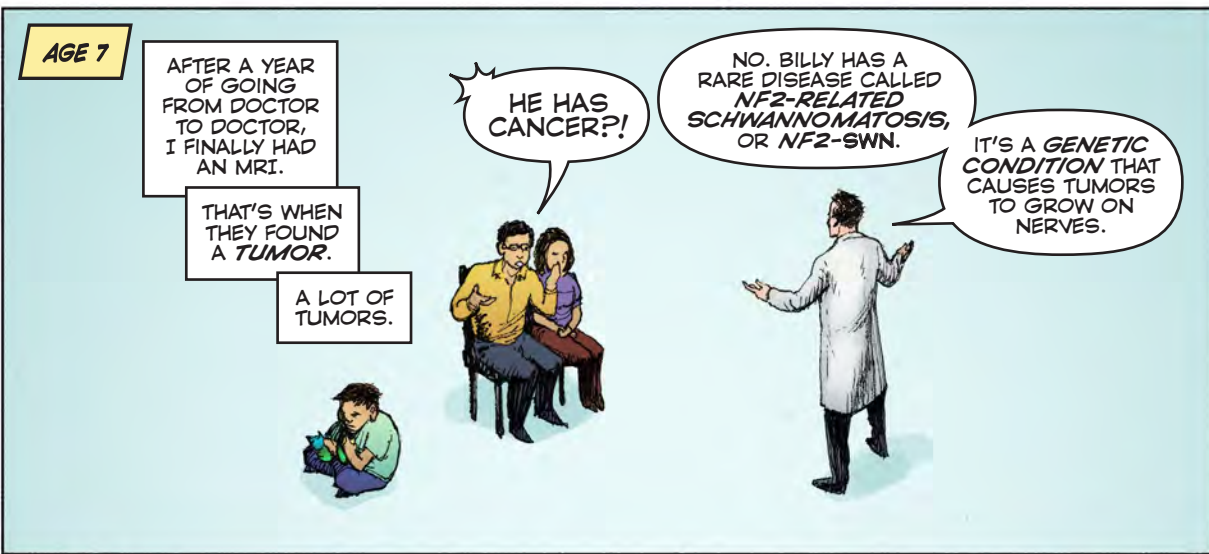
THAT'S WHEN THEY FOUND A TUMOR.

A LOT OF TUMORS.

HE HAS CANCER?!

NO. BILLY HAS A RARE DISEASE CALLED **NF2-RELATED SCHWANNOMATOSIS**, OR **NF2-SWN**.

IT'S A **GENETIC CONDITION** THAT CAUSES TUMORS TO GROW ON NERVES.

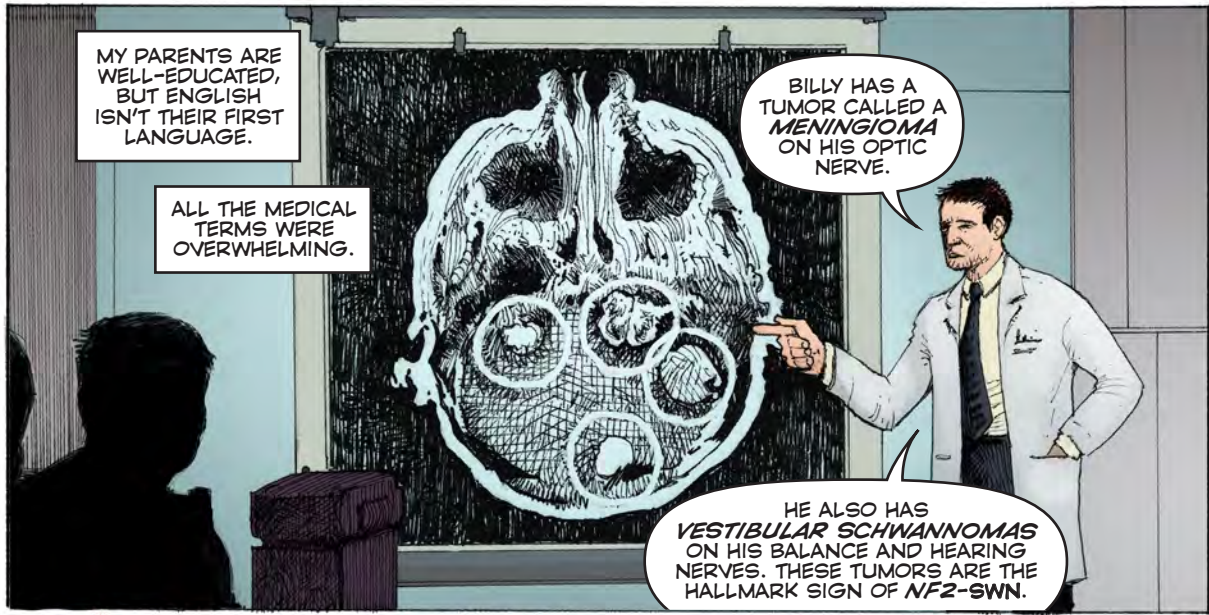


MY PARENTS ARE WELL-EDUCATED, BUT ENGLISH ISN'T THEIR FIRST LANGUAGE.

ALL THE MEDICAL TERMS WERE OVERWHELMING.

BILLY HAS A TUMOR CALLED A **MENINGIOMA** ON HIS OPTIC NERVE.

HE ALSO HAS **VESTIBULAR SCHWANNOMAS** ON HIS BALANCE AND HEARING NERVES. THESE TUMORS ARE THE HALLMARK SIGN OF **NF2-SWN**.



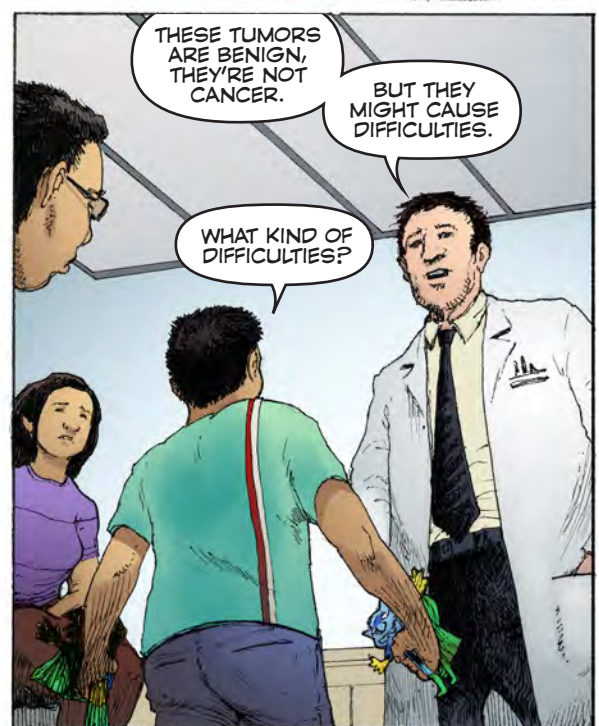
I'M NOT SURE MOST KIDS DIAGNOSED WITH A CHRONIC DISEASE UNDERSTAND HOW IT COULD AFFECT THEM.

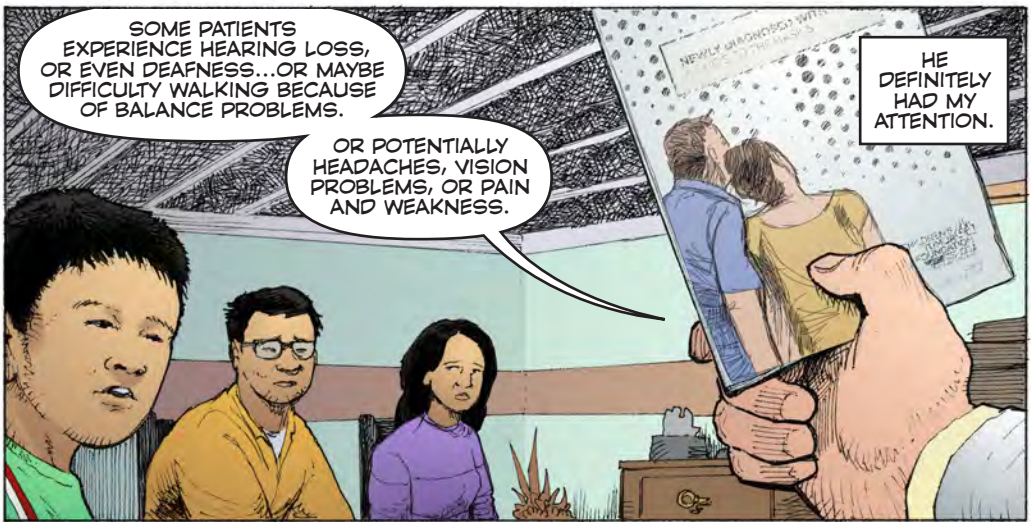
I WAS ONE OF THEM.

THESE TUMORS ARE BENIGN, THEY'RE NOT CANCER.

BUT THEY MIGHT CAUSE DIFFICULTIES.

WHAT KIND OF DIFFICULTIES?





SOME PATIENTS EXPERIENCE HEARING LOSS, OR EVEN DEAFNESS...OR MAYBE DIFFICULTY WALKING BECAUSE OF BALANCE PROBLEMS.

OR POTENTIALLY HEADACHES, VISION PROBLEMS, OR PAIN AND WEAKNESS.

HE DEFINITELY HAD MY ATTENTION.



MOST PATIENTS DON'T DEVELOP SYMPTOMS UNTIL THEY'RE IN THEIR TEENS OR TWENTIES.

I JUST TURNED SEVEN. BEING A TEENAGER SEEMED SO FAR AWAY.



HOW DID BILLY CATCH THIS?

YOU CAN'T CATCH NF2-RELATED SCHWANNOMATOSIS. IT'S SOMETHING YOU'RE BORN WITH.

IT'S DUE TO A CHANGE IN THE NF2 GENE, A GENE LOCATED ON CHROMOSOME 22.

HE MIGHT HAVE INHERITED IT FROM ONE OF YOU.

OR IT COULD BE A SPONTANEOUS OCCURRENCE, MEANING HIS GENE JUST CHANGED ON ITS OWN.

NONE OF IT SEEMED TO MAKE SENSE. TO ANY OF US.

CHÚNG TA CÓ THỂ LÀM GÌ?

EM KHÔNG BIẾT

CAN YOU CURE IT?

THERE IS NO CURE. AT LEAST... NOT YET.

AGE 13

AS A CHILD, I DIDN'T REALLY UNDERSTAND NF2-SWN, AND I DIDN'T THINK IT WAS VERY SIGNIFICANT.

AS I GREW UP, IT STARTED TO MATTER.

ONE OF YOUR TUMORS HAS GROWN RAPIDLY. WE NEED TO CONSIDER SURGERY.

ON MY BRAIN?

YES. WITHOUT IT, YOU MAY LOSE YOUR VISION.

I COULD GO BLIND?!

IN IMMIGRANT FAMILIES, SOMETIMES THE CHILD MUST TRANSLATE MEDICAL TERMS FOR THE PARENTS.

WHICH CAN MAKE A CONFUSING SITUATION EVEN MORE SCARY.

GIẢI PHẪU? KHÔNG CÓ LỰA CHỌN NÀO KHÁC?

...I DON'T KNOW, OKAY!!!

I DIDN'T KNOW WHAT TO DO. I FELT LIKE I HAD TO FIGURE IT OUT ALL BY MYSELF.

SLAM!





I WENT BACK TO MY FRESHMAN YEAR WITH A GIANT SCAR AND STAPLES ON MY FOREHEAD.

ONLY 1 IN 25,000 PEOPLE HAVE NF2-SWN. I DIDN'T THINK ANYONE WOULD UNDERSTAND.

HEY, BILLY. WANNA COME OVER LATER?

HE NEVER WANTS TO HANG OUT ANYMORE.

NO, THANKS.

I FELT TERRIBLY ALONE.

AGE 18

BUT THE SCAR HEALED, AND I GRADUATED AT THE TOP OF MY CLASS.

MY NEXT STOP: UNIVERSITY OF CALIFORNIA, SAN DIEGO.

AGE 21

THEN ON TO UCLA FOR MEDICAL SCHOOL.

I DECIDED TO BECOME A PHYSICIAN.

PARTLY BECAUSE OF THE CONNECTION I FELT AS A PATIENT LIVING WITH NF2-SWN.

BUT I LIVED IN CONSTANT FEAR OF MY TUMORS GROWING.

IN COLLEGE, ONE OF THEM TRIPLED IN SIZE.

MY FIRST YEAR AT MEDICAL SCHOOL, IT TRIPLED AGAIN.

AGE 18

AGE 20

AGE 22

AGE 23



THAT'S WHEN THE HEARING LOSS BEGAN, ON MY LEFT SIDE.

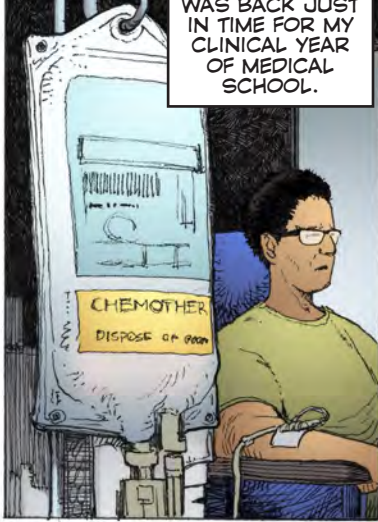
HOW CAN I BECOME A DOCTOR WHEN I CAN'T EVEN TAKE CARE OF MYSELF?

I STARTED TO DOUBT EVERYTHING. ESPECIALLY MYSELF.

AGE 23

FORTUNATELY, I STARTED A NEW TREATMENT. IT CHANGED EVERYTHING.

MY HEARING WAS BACK JUST IN TIME FOR MY CLINICAL YEAR OF MEDICAL SCHOOL.



IN THE HOSPITAL, I HAD A TWELVE-YEAR-OLD PATIENT WHO HAD CANCER IN HIS LEG.

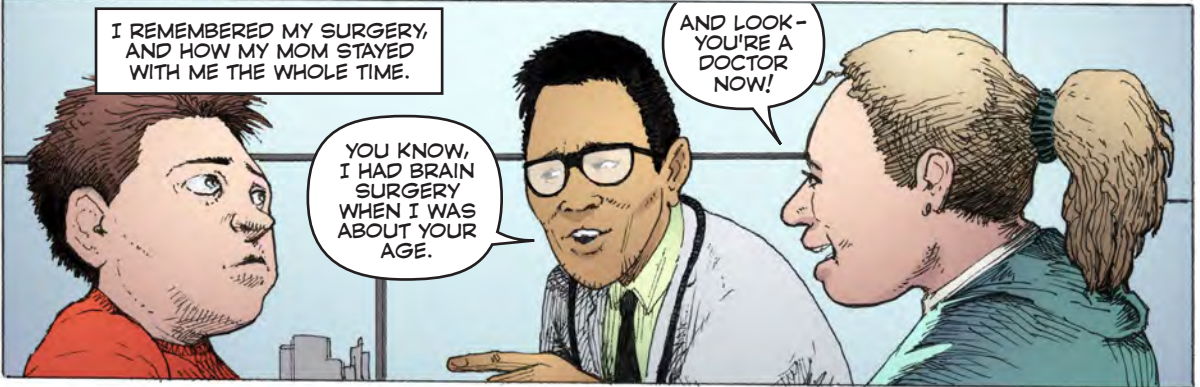
HE HAD JUST UNDERGONE AN ABOVE-THE-KNEE AMPUTATION.



I REMEMBERED MY SURGERY, AND HOW MY MOM STAYED WITH ME THE WHOLE TIME.

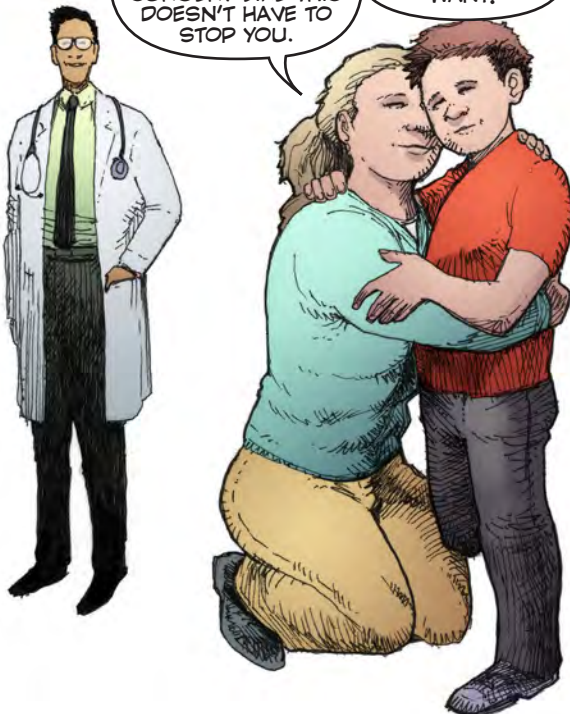
YOU KNOW, I HAD BRAIN SURGERY WHEN I WAS ABOUT YOUR AGE.

AND LOOK - YOU'RE A DOCTOR NOW!



SEE JOHNNY, YOU CAN DO IT TOO. SURGERY LIKE THIS DOESN'T HAVE TO STOP YOU.

YOU CAN DO ANYTHING YOU WANT!



IT MADE ME REALIZE HOW MUCH MY EXPERIENCE CAN INSPIRE YOUNG PATIENTS.



THE PRESENT.
AGE 25

I NEVER THOUGHT I COULD
BECOME A DOCTOR. IT SEEMED
TOO FAR OUT OF REACH.

MY HEARING
IS STABLE
NOW.

BUT I'M UNDER
NO ILLUSION
THAT THINGS
WILL STAY THIS
WAY FOREVER.

I REALIZE
HOW LIMITED
MY TIME IS.

OUR CURRENT DRUGS
ONLY HELP SO MUCH...

ONE THAT WILL
CURE NF2-SWN.

BUT UNTIL
THEN, WE
KEEP ON
FIGHTING.

...HOPEFULLY WE CAN
BUY ENOUGH TIME,
UNTIL WE FIND A MORE
PERMANENT THERAPY.

**SYNODOS
FOR NF2:
LET'S END NF**

CHILDREN'S TUMOR
FOUNDATION

A WISE MENTOR ONCE
TOLD ME, LIFE IS 10%
WHAT HAPPENS, AND 90%
HOW YOU RESPOND.

I WANT TO
RESPOND
LOUDLY AND
CLEARLY.

THIS DISEASE WILL NOT LIMIT ME,
BUT IT WILL MOLD ME INTO THE
BEST PHYSICIAN I CAN BE.

I'VE BEEN IN
YOUR SHOES AND I
KNOW HOW SCARED
AND CONFUSED YOU
MUST FEEL, MARIA.

BUT I DID
IT, AND I KNOW
YOU CAN TOO.

I CAN'T MAKE IT
ALL GO AWAY, BUT
I CAN HELP YOU
UNDERSTAND.

YOU'RE
NOT ALONE.
I'LL JOIN
YOU ON YOUR
JOURNEY IF
YOU'LL HAVE
ME.

I'D LIKE
THAT.