



TURBO & SCOTT

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The depiction of tuberous sclerosis complex (TSC) as displayed by the characters in this graphic novel are representative of individual experiences and are not meant to characterise the broad manifestations and behaviours of people living with TSC.

"I HAVE TSC, BUT IT DOESN'T HAVE ME"

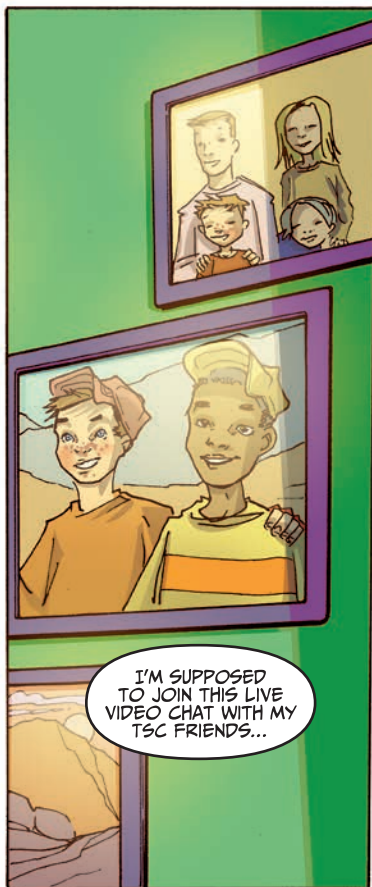
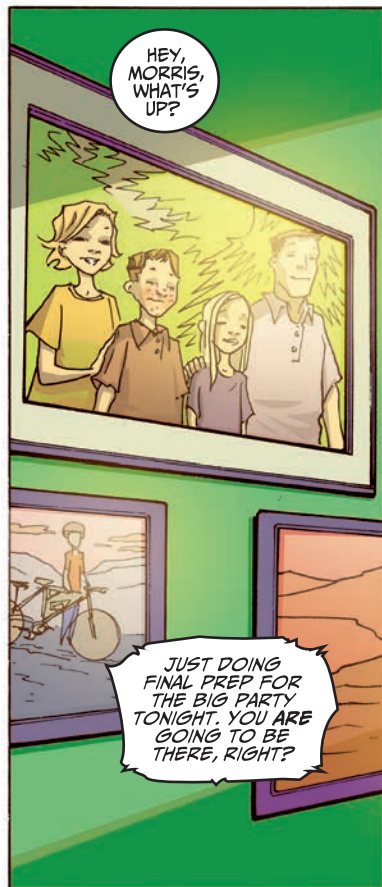
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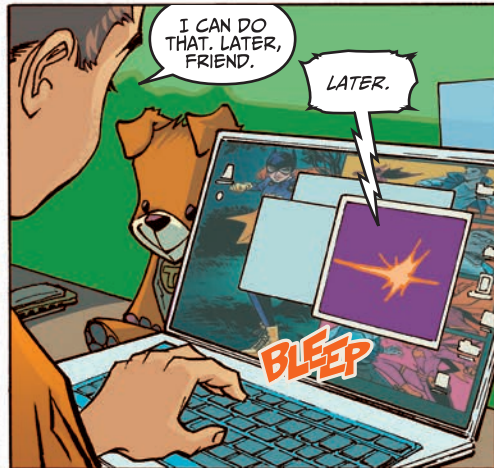
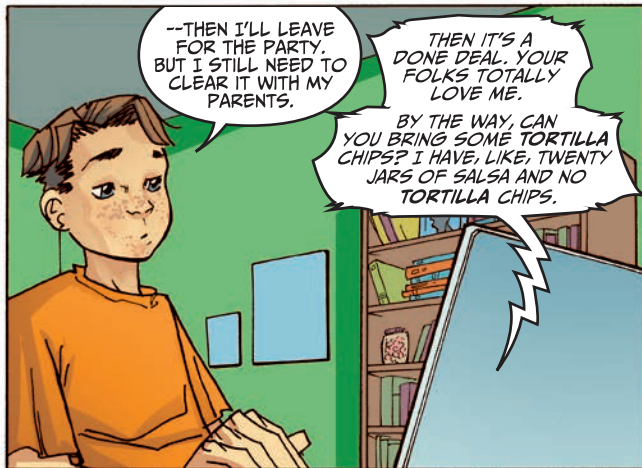
tsc
tuberous sclerosis
association

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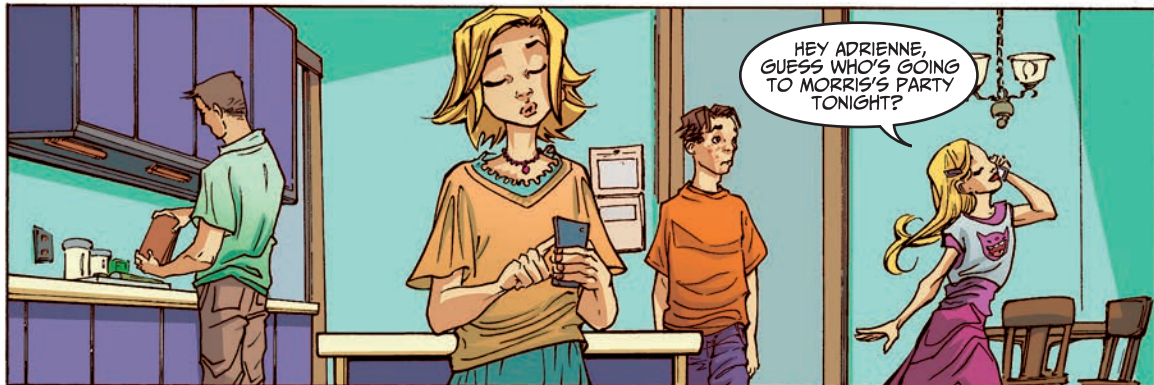
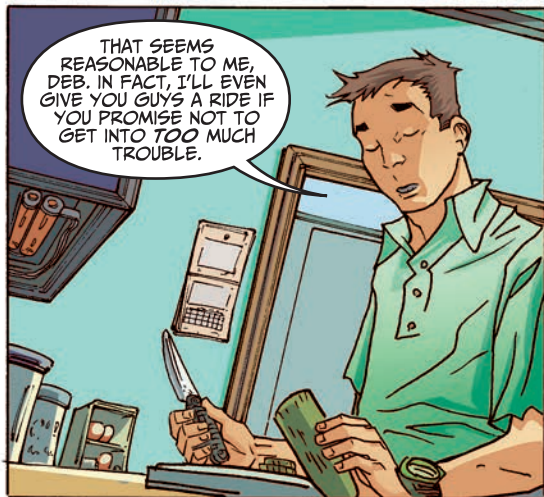


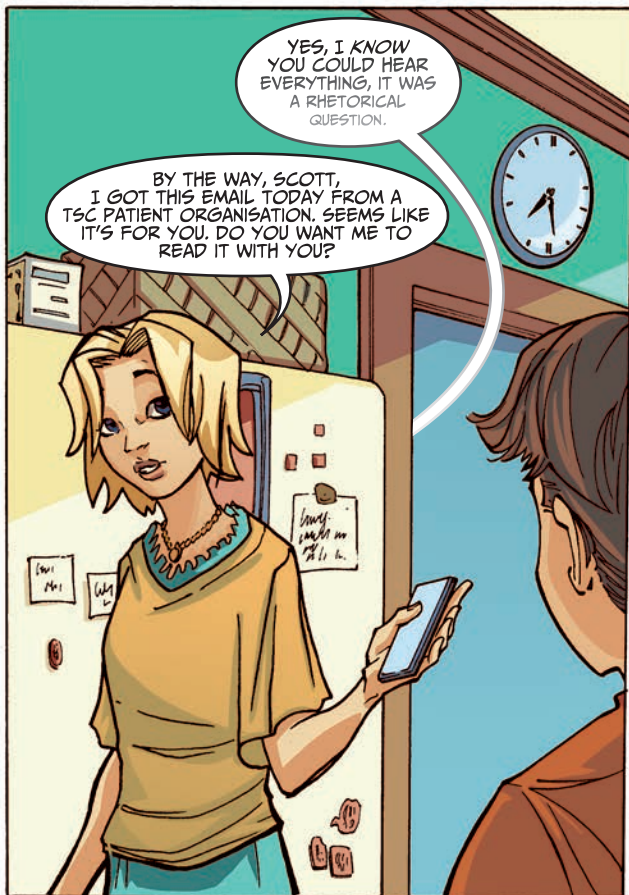
TURBO & SCOTT

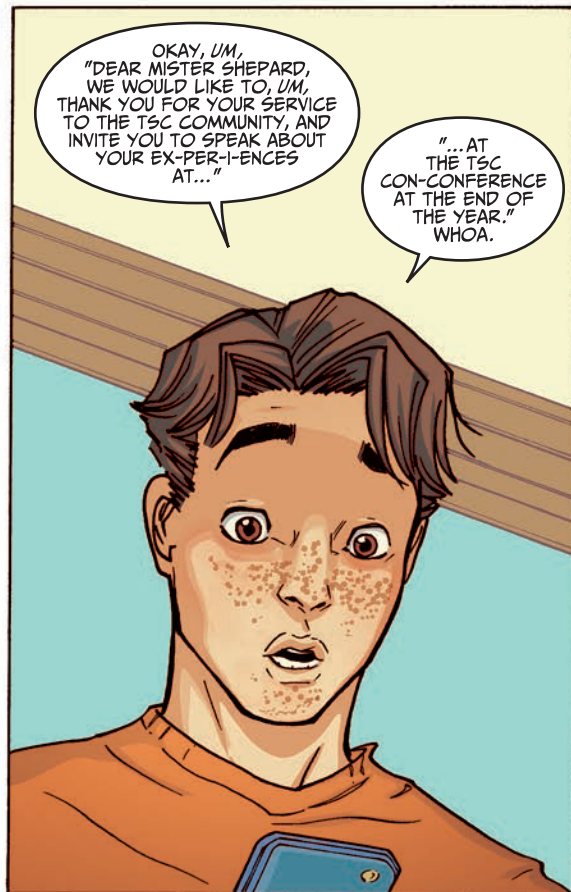


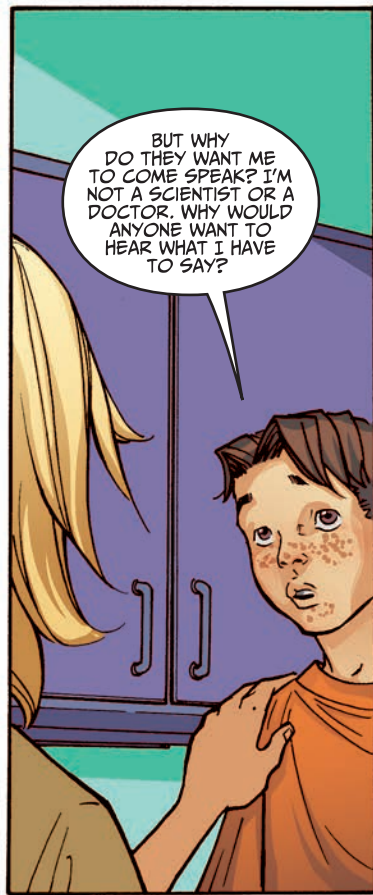
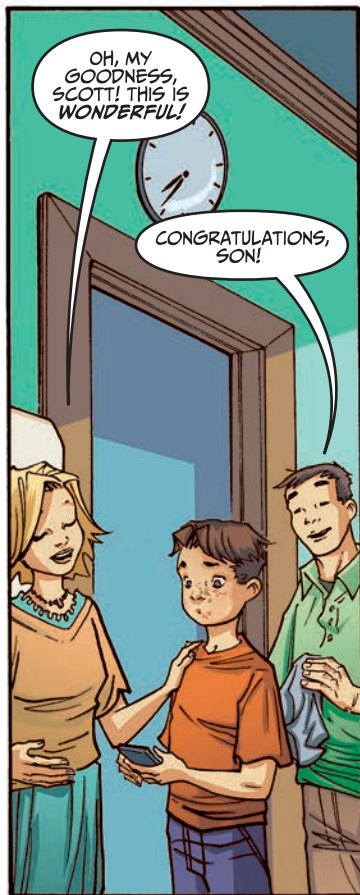


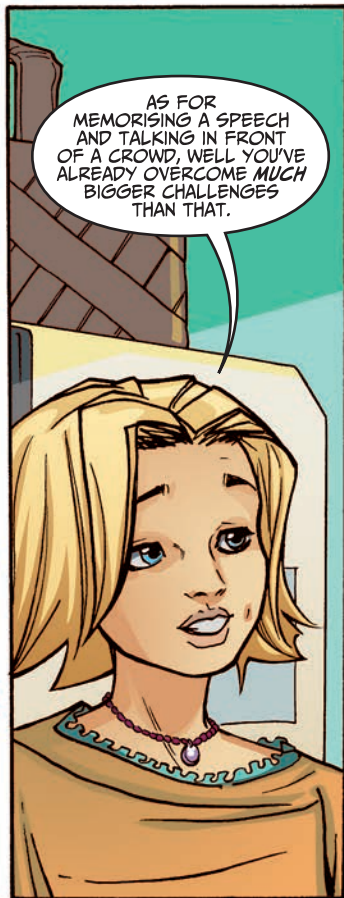


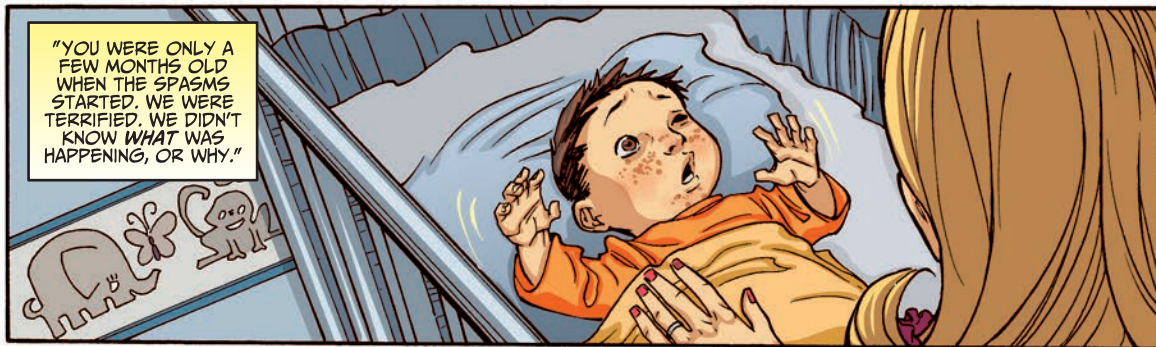




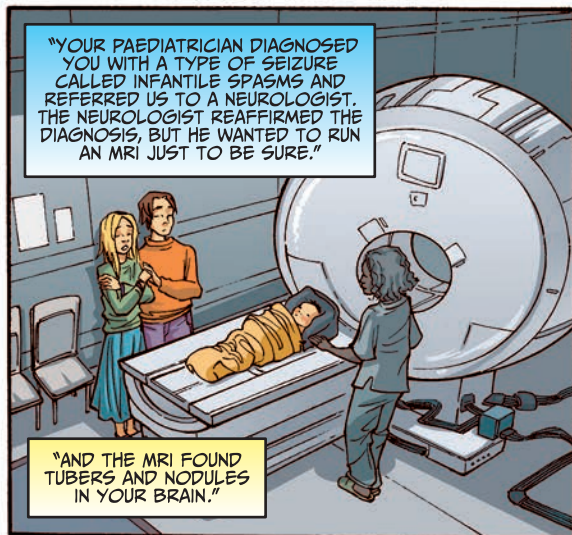






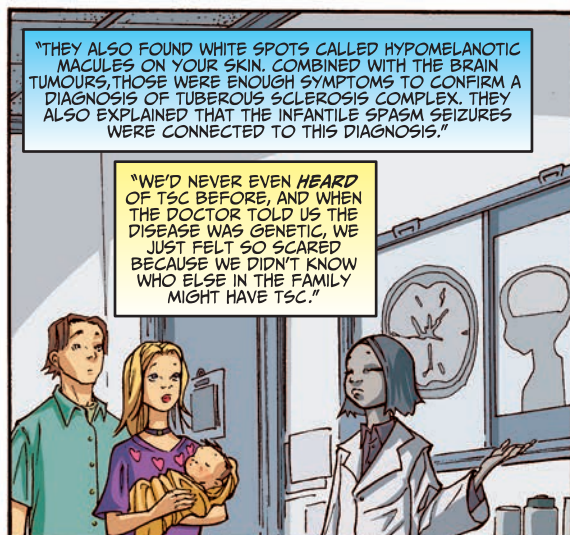


"YOU WERE ONLY A FEW MONTHS OLD WHEN THE SPASMS STARTED. WE WERE TERRIFIED. WE DIDN'T KNOW *WHAT* WAS HAPPENING, OR WHY."



"YOUR PAEDIATRICIAN DIAGNOSED YOU WITH A TYPE OF SEIZURE CALLED INFANTILE SPASMS AND REFERRED US TO A NEUROLOGIST. THE NEUROLOGIST REAFFIRMED THE DIAGNOSIS, BUT HE WANTED TO RUN AN MRI JUST TO BE SURE."

"AND THE MRI FOUND TUBERS AND NODULES IN YOUR BRAIN."

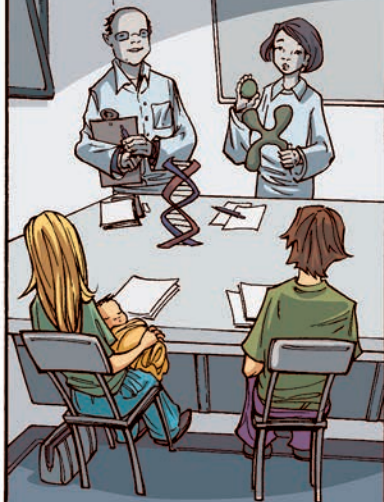


"THEY ALSO FOUND WHITE SPOTS CALLED HYPOMELANOTIC MACULES ON YOUR SKIN. COMBINED WITH THE BRAIN TUMOURS, THOSE WERE ENOUGH SYMPTOMS TO CONFIRM A DIAGNOSIS OF TUBEROUS SCLEROSIS COMPLEX. THEY ALSO EXPLAINED THAT THE INFANTILE SPASM SEIZURES WERE CONNECTED TO THIS DIAGNOSIS."

"WE'D NEVER EVEN *HEARD* OF TSC BEFORE, AND WHEN THE DOCTOR TOLD US THE DISEASE WAS GENETIC, WE JUST FELT SO SCARED BECAUSE WE DIDN'T KNOW WHO ELSE IN THE FAMILY MIGHT HAVE TSC."

"BUT NO ONE ELSE IN OUR FAMILY HAS TSC. I GOT MINE FROM A, UM-UM, RANDOM GENETIC MUTATION."

"WE KNOW THAT NOW, SCOTT, BUT WE DIDN'T KNOW IT *THEN*. NOT UNTIL THE PEOPLE AT THE TSC CLINIC BEGAN TEACHING US ABOUT THE DISEASE."

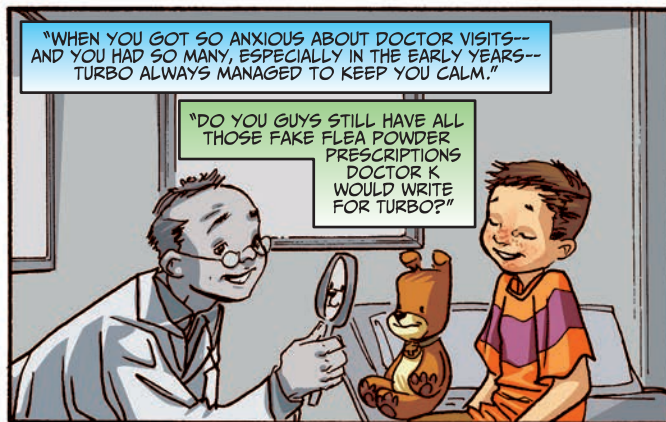
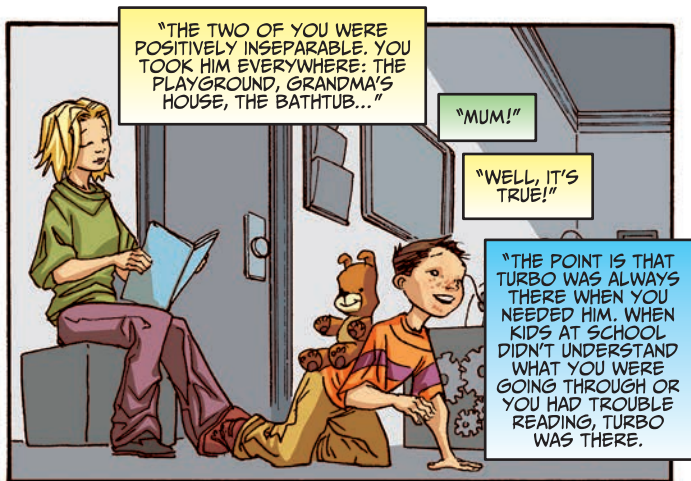


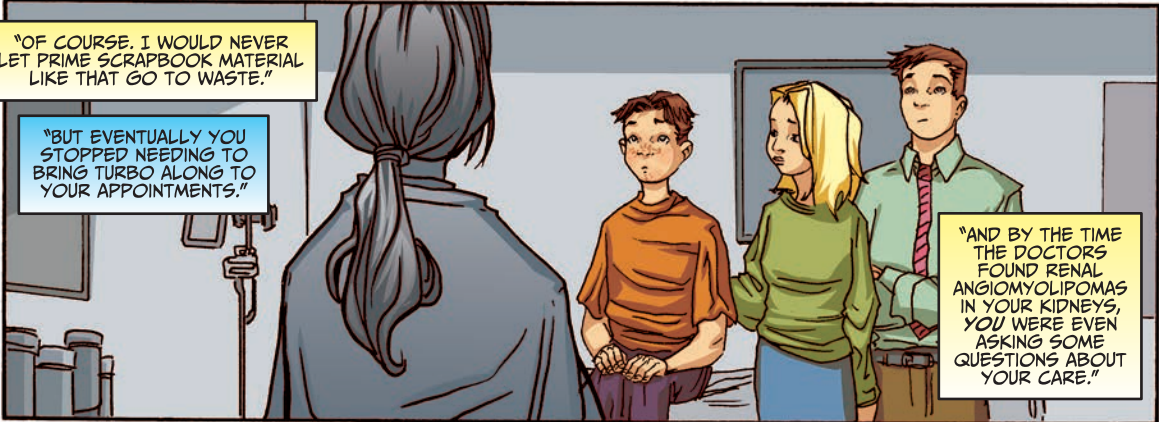
"THEN WE GOT TERRIFIED ALL OVER AGAIN WHEN WE LEARNED THERE WERE SO MANY SYMPTOMS AND THAT EVERY TSC CASE EXPRESSES ITSELF DIFFERENTLY."

"WE DIDN'T KNOW WHAT TO EXPECT. WE JUST KNEW IT WOULD BE A DIFFICULT ROAD FOR ALL OF US."



"THANKFULLY WE DIDN'T HAVE TO TRAVEL IT ALL BY OURSELVES. DOCTORS AND NURSES HELPED A LOT, AND WE EVEN MET A FEW OTHER PARENTS. TODAY THOUGH, THERE'S AN AMAZING TSC SUPPORT NETWORK!"





"OF COURSE. I WOULD NEVER LET PRIME SCRAPBOOK MATERIAL LIKE THAT GO TO WASTE."

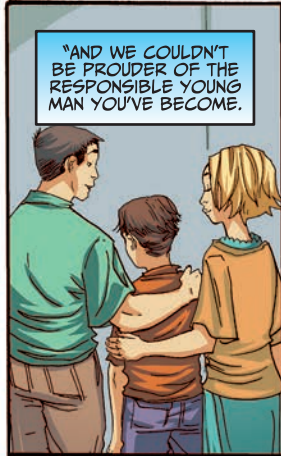
"BUT EVENTUALLY YOU STOPPED NEEDING TO BRING TURBO ALONG TO YOUR APPOINTMENTS."

"AND BY THE TIME THE DOCTORS FOUND RENAL ANGIOMYOLIPOMAS IN YOUR KIDNEYS, YOU WERE EVEN ASKING SOME QUESTIONS ABOUT YOUR CARE."

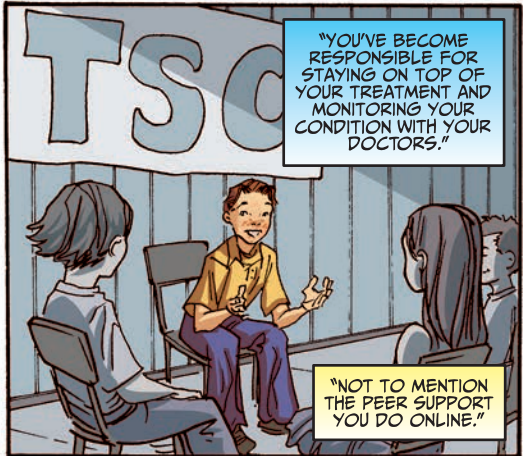


"SURE, I ASKED A LOT OF QUESTIONS, BUT YOU GUYS WERE STILL THERE BACKING ME UP."

"AND WE ALWAYS WILL BE, BECAUSE YOU'LL ALWAYS BE OUR LITTLE BOY."

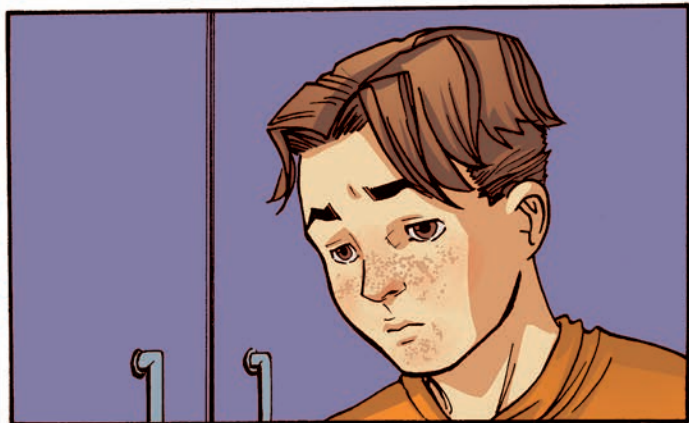
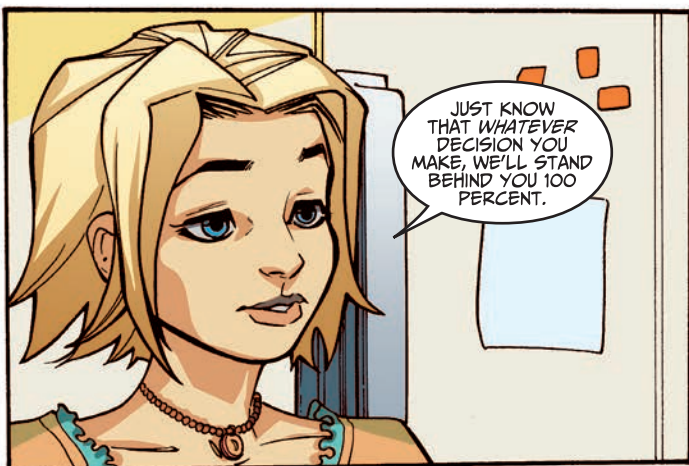
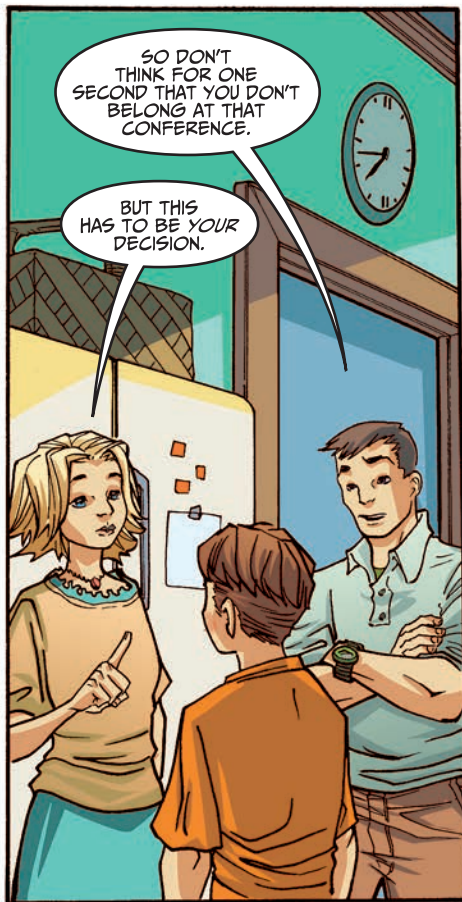


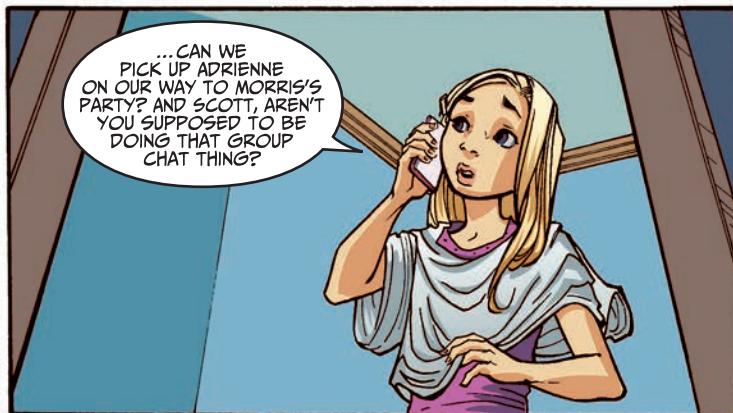
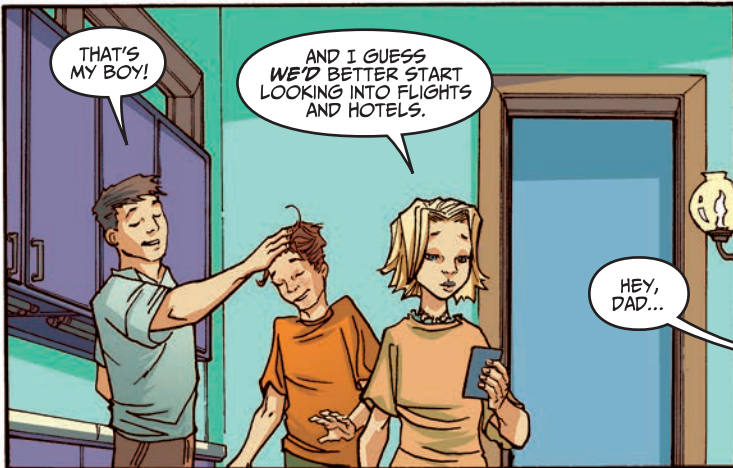
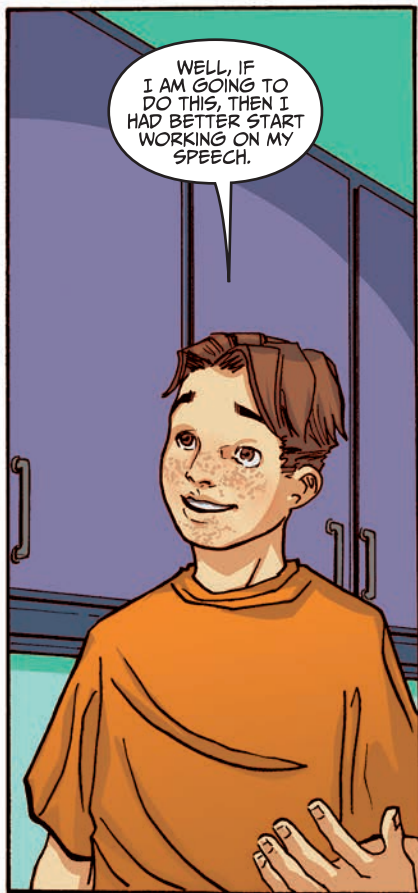
"AND WE COULDN'T BE PROUDER OF THE RESPONSIBLE YOUNG MAN YOU'VE BECOME."



"YOU'VE BECOME RESPONSIBLE FOR STAYING ON TOP OF YOUR TREATMENT AND MONITORING YOUR CONDITION WITH YOUR DOCTORS."

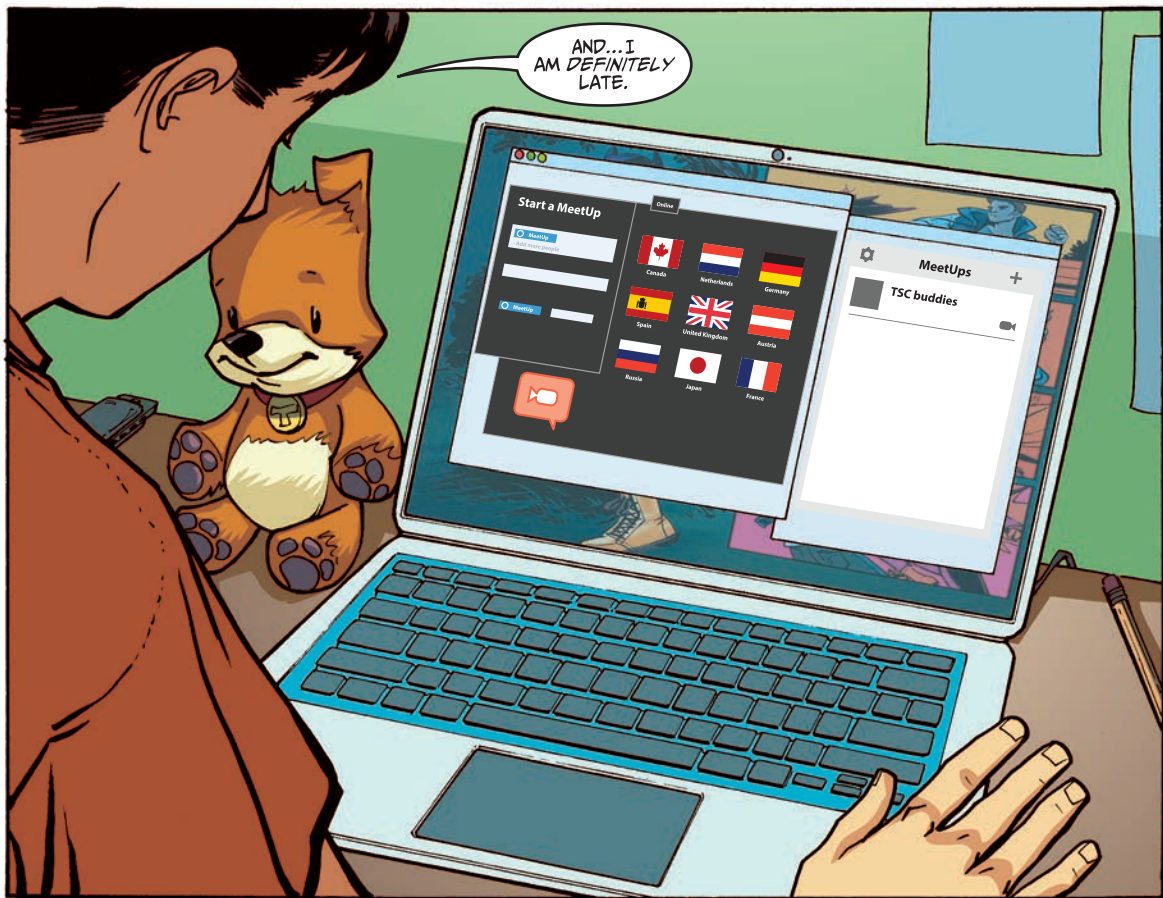
"NOT TO MENTION THE PEER SUPPORT YOU DO ONLINE."







AND...I
AM DEFINITELY
LATE.



TWO HOURS
LATER...

GREAT
CHATTING WITH
EVERYBODY. SEE
YOU SOON.



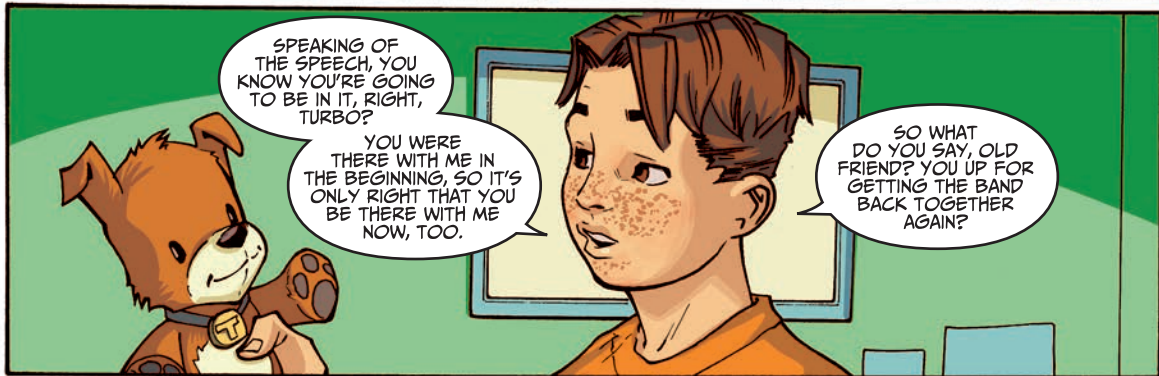
ALWAYS SO
FUN TO CHAT WITH
MY TSC FRIENDS.
MAYBE I ACTUALLY
CAN PULL OFF
THIS SPEECH.

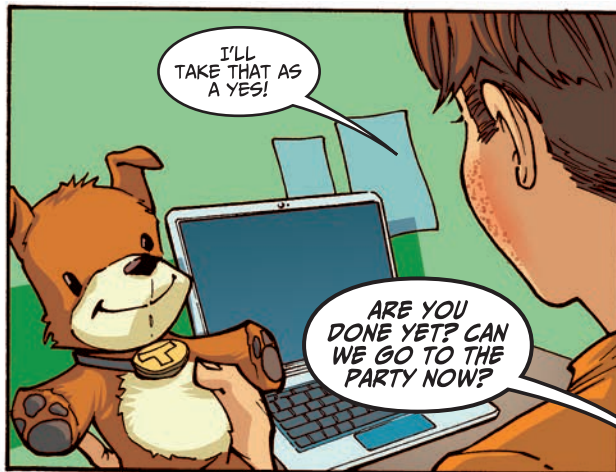


SPEAKING OF
THE SPEECH, YOU
KNOW YOU'RE GOING
TO BE IN IT, RIGHT,
TURBO?

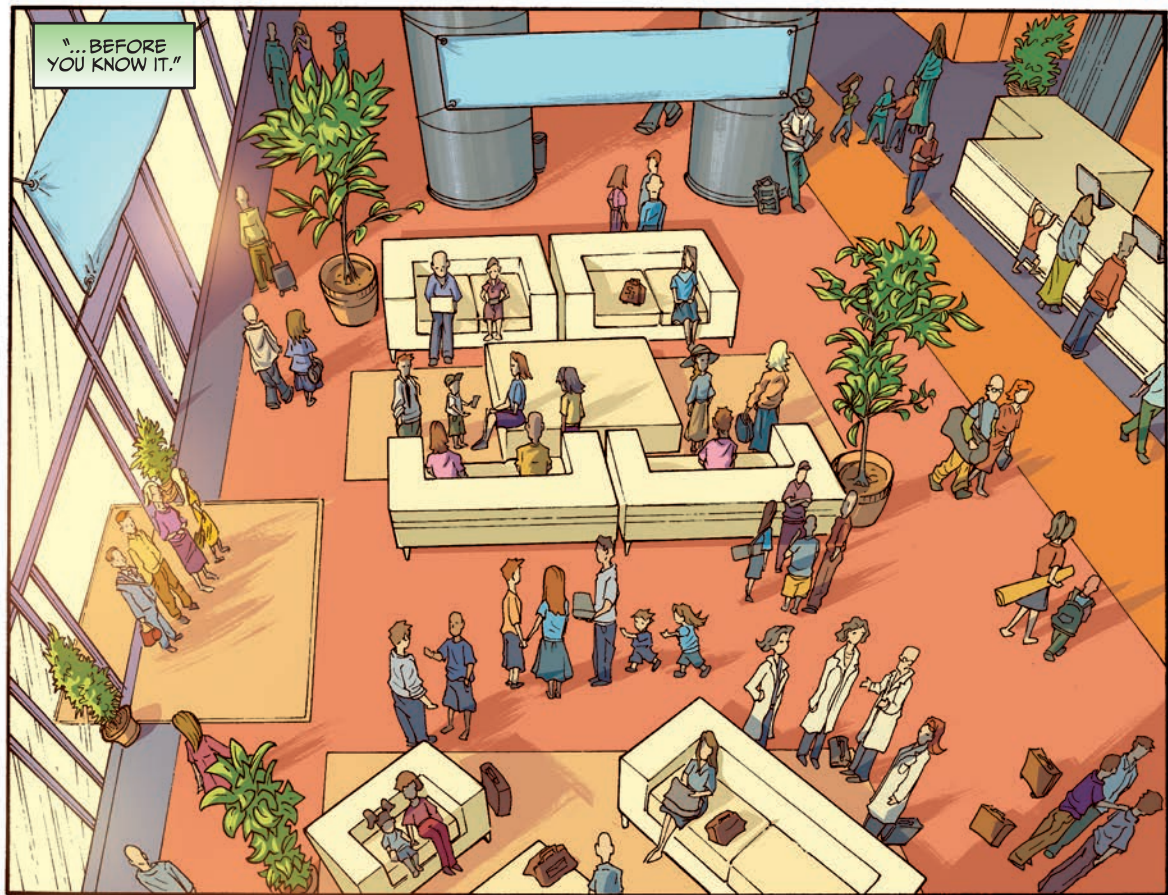
YOU WERE
THERE WITH ME IN
THE BEGINNING, SO IT'S
ONLY RIGHT THAT YOU
BE THERE WITH ME
NOW, TOO.

SO WHAT
DO YOU SAY, OLD
FRIEND? YOU UP FOR
GETTING THE BAND
BACK TOGETHER
AGAIN?

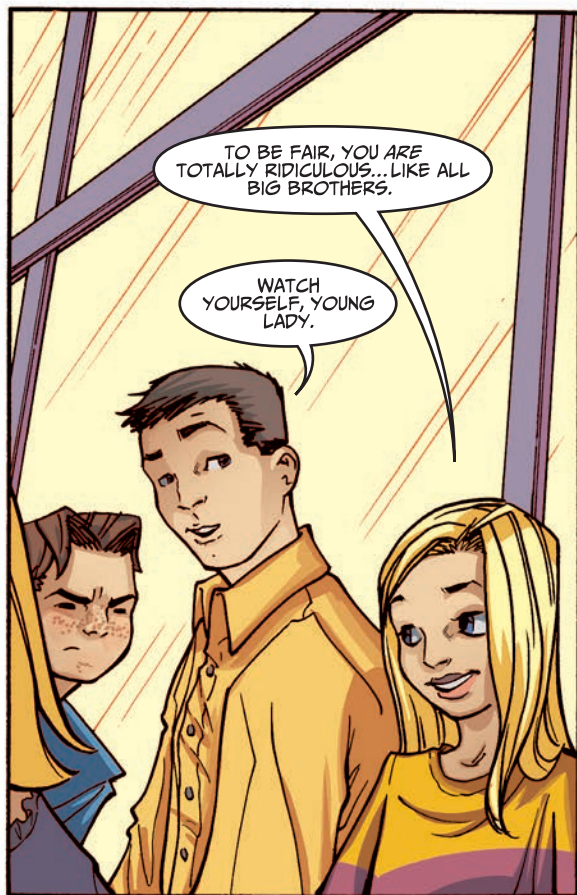


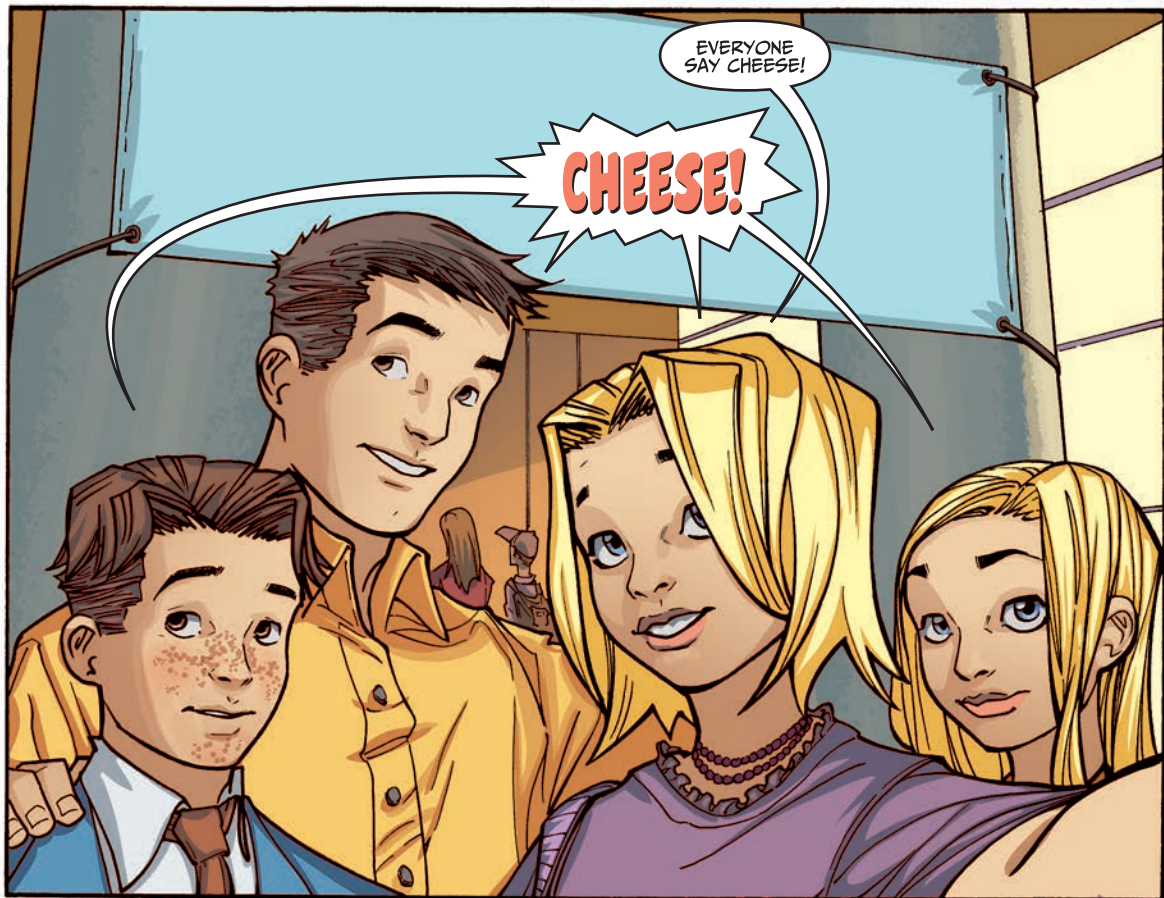


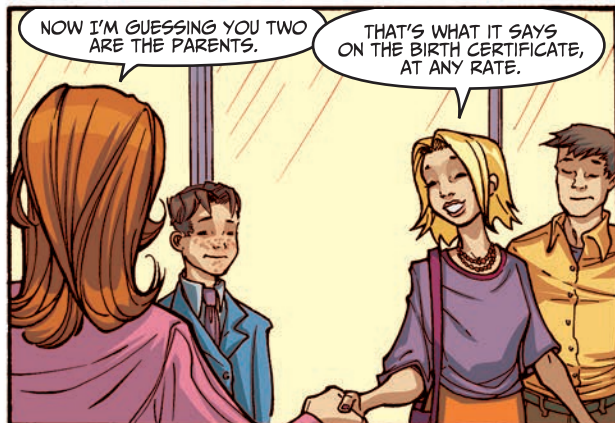
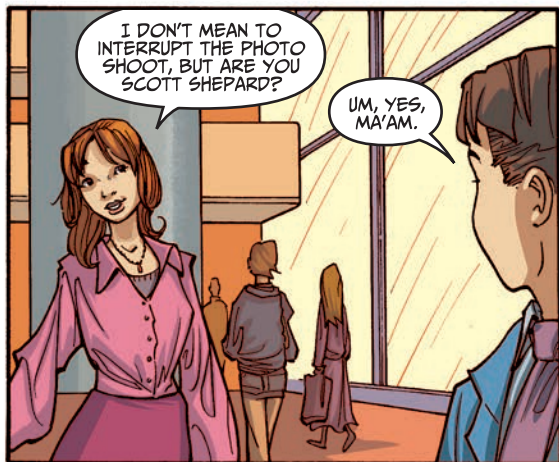
"... BEFORE
YOU KNOW IT."

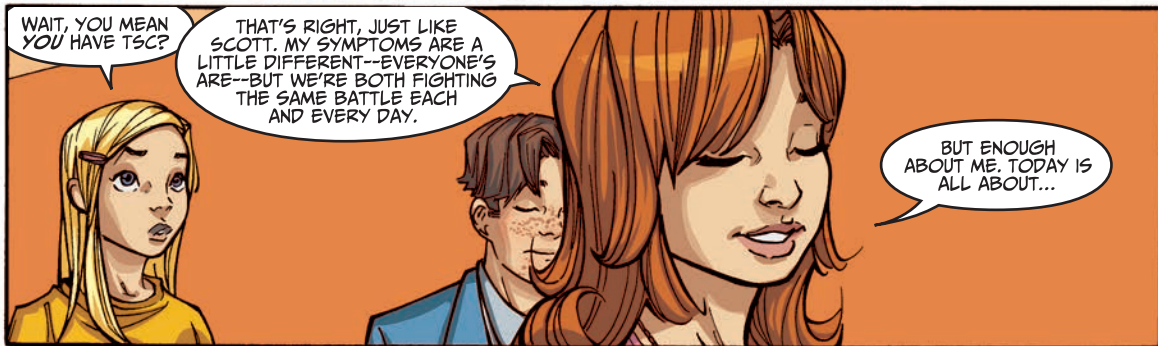
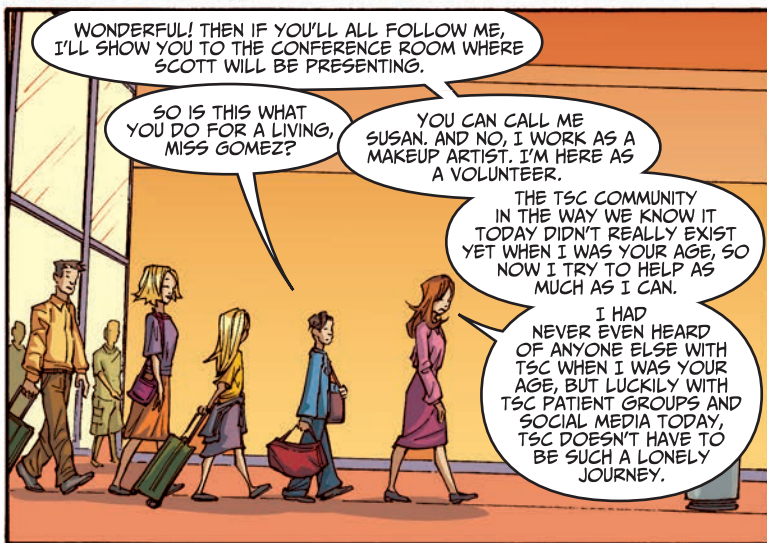












SCOTT SHEPARD,
A NAME MANY OF YOU
PROBABLY ALREADY KNOW
SINCE HE PRACTICALLY LIVES
ON SOCIAL MEDIA.

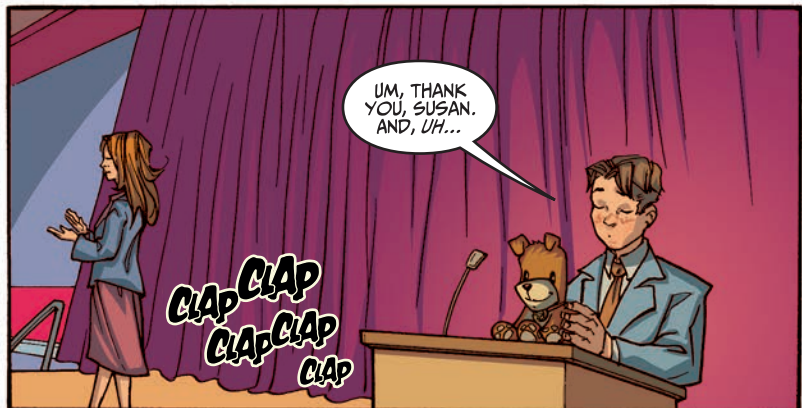
HE'S ONE
OF THE MOST ACTIVE
PEOPLE IN THE TSC SOCIAL
MEDIA NETWORK, AND HE'S
TRAVELED A LONG WAY TO
SHARE HIS STORY
WITH US.

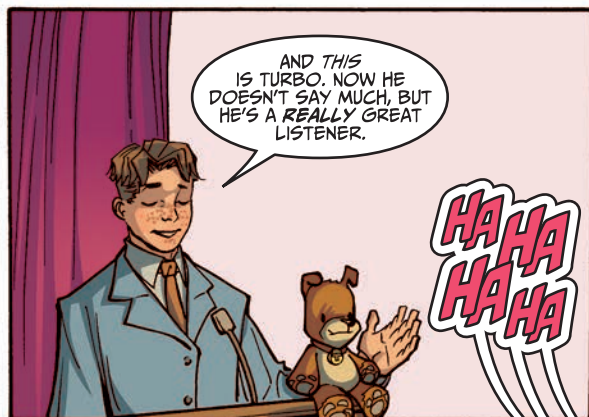


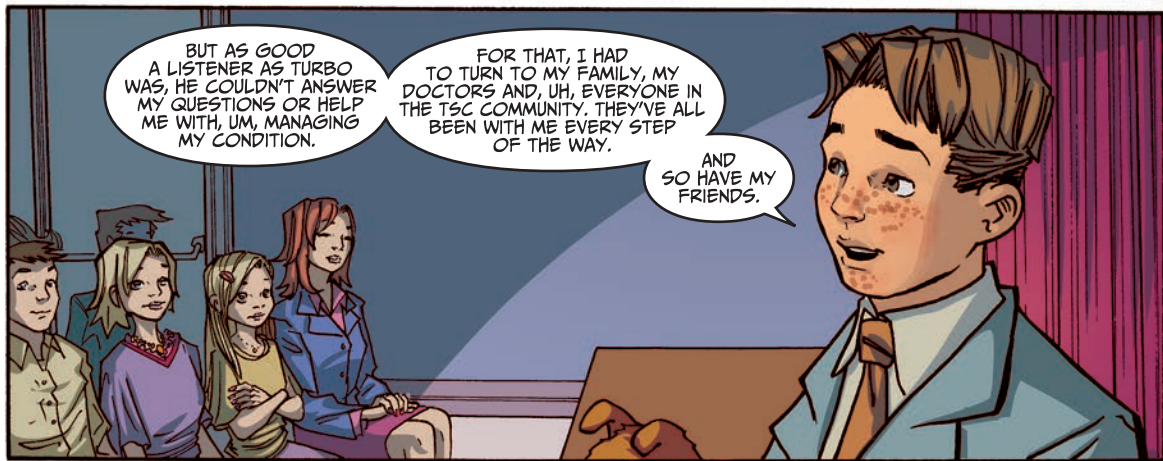
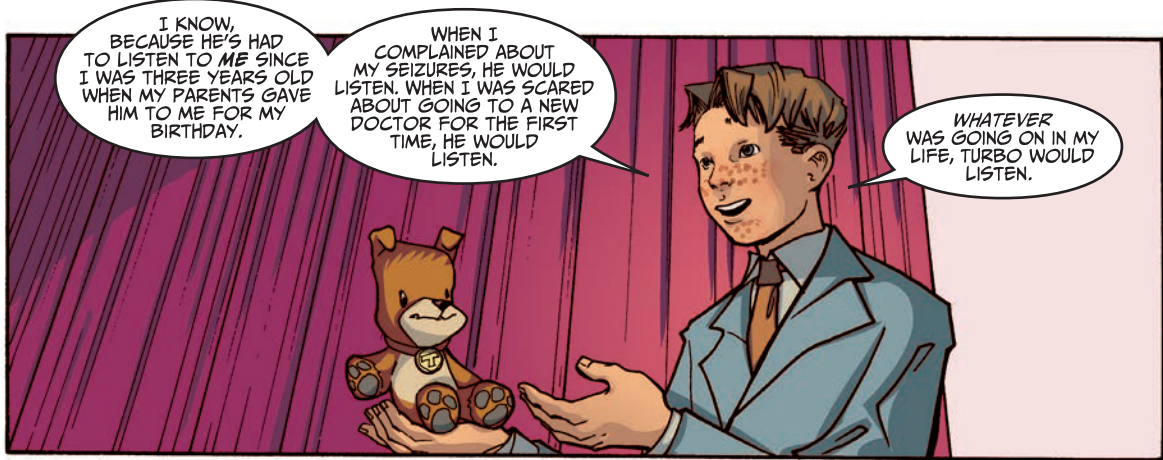
SO LET'S
GIVE HIM A WARM,
TSC COMMUNITY
WELCOME.



UM, THANK
YOU, SUSAN.
AND, UH...







I WAS... TEASED A LOT IN SCHOOL BY THE MEAN KIDS. THEY MADE FUN OF ME FOR HAVING WEIRD BUMPS ON MY SKIN AND FOR HAVING TROUBLE READING AND KEEPING UP IN CLASS, AND FOR JUST BEING *DIFFERENT*.

BUT MY FRIEND MORRIS DIDN'T SEE OUR DIFFERENCES. HE ONLY SAW SOMEONE WHO LIKED ATHLETICS AND WATCHING SCI-FI MOVIES AND READING COMIC BOOKS, JUST LIKE HE DID.

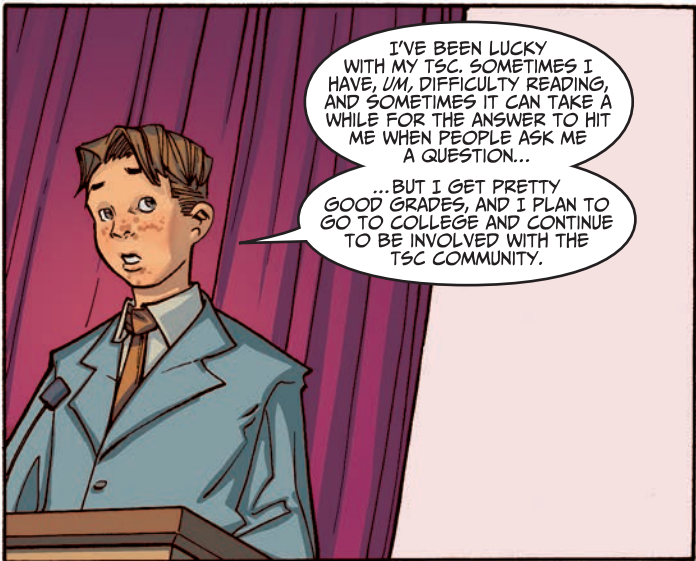
MORRIS DIDN'T SEE MY TSC, HE JUST SAW *ME*.





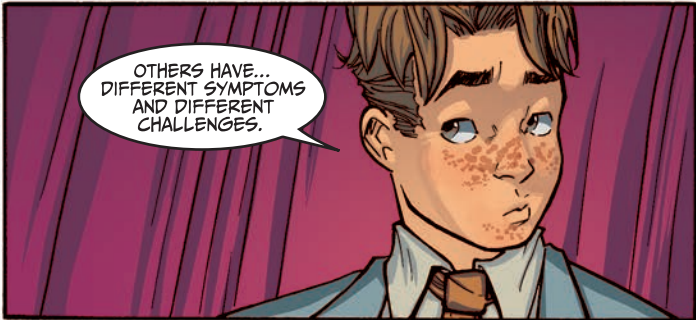
SO MANY PEOPLE--
NOT TO MENTION, UH,
STUFFED DOGS--HAVE BEEN
THERE FOR **ME** WHEN I
NEEDED THEM.

THAT'S
WHY I TRY TO
TALK TO AS MANY
PEOPLE WITH TSC AS
I CAN, SO THAT I CAN
BE THERE FOR
OTHERS.



I'VE BEEN LUCKY
WITH MY TSC. SOMETIMES I
HAVE, UH, DIFFICULTY READING,
AND SOMETIMES IT CAN TAKE A
WHILE FOR THE ANSWER TO HIT
ME WHEN PEOPLE ASK ME
A QUESTION...

...BUT I GET PRETTY
GOOD GRADES, AND I PLAN TO
GO TO COLLEGE AND CONTINUE
TO BE INVOLVED WITH THE
TSC COMMUNITY.



OTHERS HAVE...
DIFFERENT SYMPTOMS
AND DIFFERENT
CHALLENGES.

I TALK ONLINE
WITH TEENS AND ADULTS
FROM ALL AROUND THE WORLD
WHO HAVE TSC. A LOT OF THEM
HAVE TROUBLE TALKING TO
OTHERS AND INITIALLY
MAKING FRIENDS.



SOME, LIKE MY
FRIEND FROM INDIA, ALSO
HAVE PROBLEMS WITH ANXIETY
AND, UM, DEPRESSION, AND
EVERY DAY CAN FEEL LIKE
A STRUGGLE.

AND A GIRL MY AGE I
KNOW FROM MISSOURI WAS JUST
DIAGNOSED WITH LAM, A, UH, SERIOUS
LUNG DISEASE WITH A, UM, CRAZY LONG
NAME, THAT MOSTLY AFFECTS WOMEN.
LUCKILY, SHE WAS GETTING TESTED
AND CAUGHT IT EARLY.





BUT WHATEVER
OUR SYMPTOMS, WE
ALL HAVE A, UM, LIFETIME
OF DOCTOR VISITS AND TESTS
AND SCANS AND DIFFERENT
TREATMENTS TO LOOK
FORWARD TO.

BECAUSE
NEW SYMPTOMS
CAN... EMERGE AT ANY
TIME AND, UH, WE HAVE
TO BE RESPONSIBLE
FOR OUR OWN TSC
MANAGEMENT AS
WE, UM, GROW
UP.

TSC FACTS

- TSC MANIFESTATIONS CHANGE OVER TIME.
- BECAUSE TSC IS A LIFELONG CONDITION, INDIVIDUALS NEED TO BE REGULARLY MONITORED BY A DOCTOR TO ACTIVELY MANAGE THE DISEASE OVER THE LONG TERM.

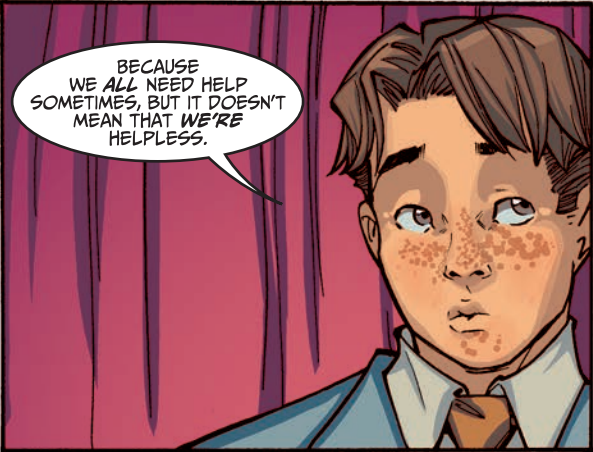


IT CAN BE
TOUGH SOMETIMES,
TO KNOW THAT WE'LL
ALWAYS HAVE TO LIVE WITH
TSC AND ALWAYS MONITOR
FOR NEW TUMOURS. BUT
WE, UH, WE **DON'T** HAVE
TO DO THIS BY
OURSELVES.



THERE ARE FAMILY, FRIENDS AND THE
TSC COMMUNITY THAT ARE READY TO
HELP. MY DOCTORS I SEE AT THE TSC
CLINIC HAVE ALWAYS BEEN THERE FOR
ME AND MY FAMILY THROUGH EVERY
NEW SYMPTOM AND TEST.

IT REALLY HELPED
ME WHEN I REALISED I
WASN'T ALONE.



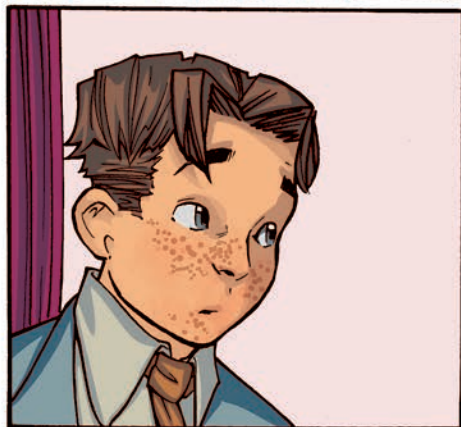
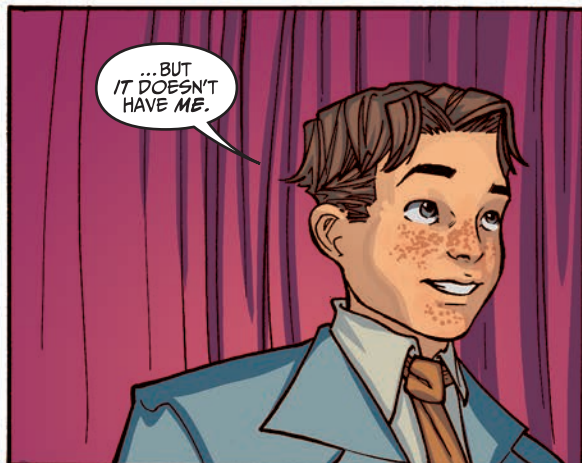
BECAUSE
WE **ALL** NEED HELP
SOMETIMES, BUT IT DOESN'T
MEAN THAT **WE'RE**
HELPLESS.

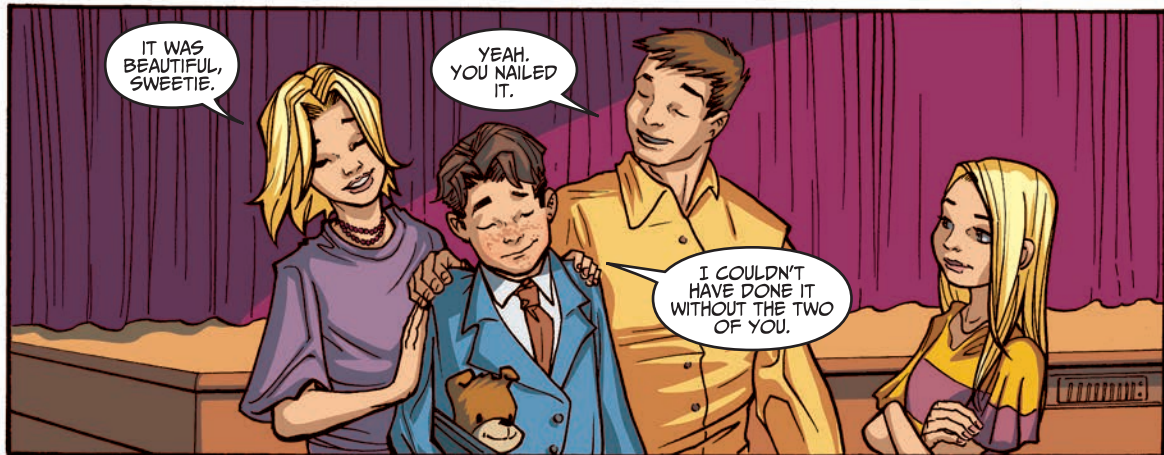
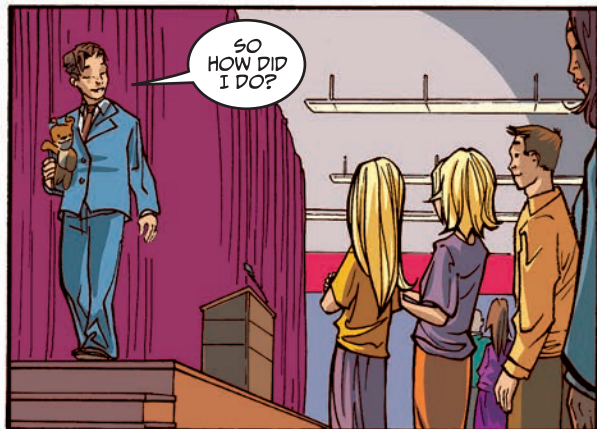
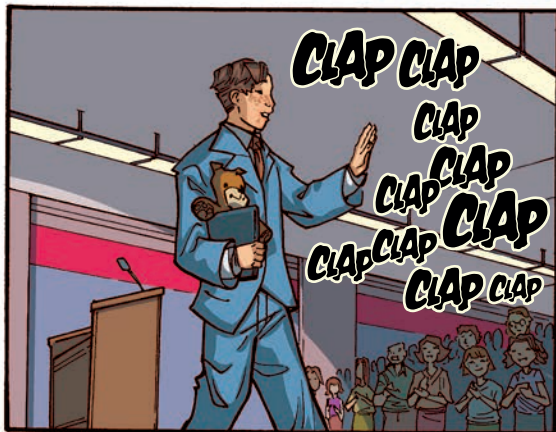
WAYS TO
MANAGE TSC ARE, UH,
GETTING BETTER, AND MEDICAL
RESEARCH IS HELPING WITH
NEW TREATMENTS
TOO.

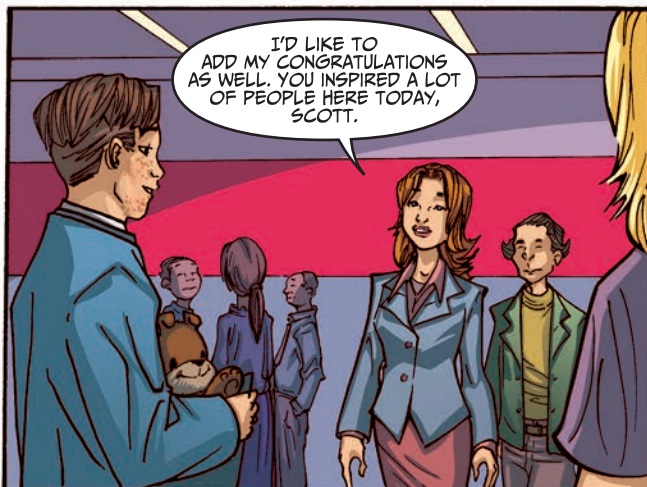
WE STILL
HAVE A LONG WAY
TO GO, BUT WE GET A
LITTLE BIT CLOSER
EVERY DAY.

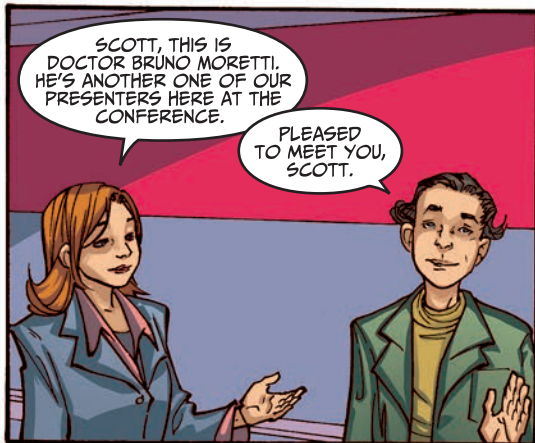
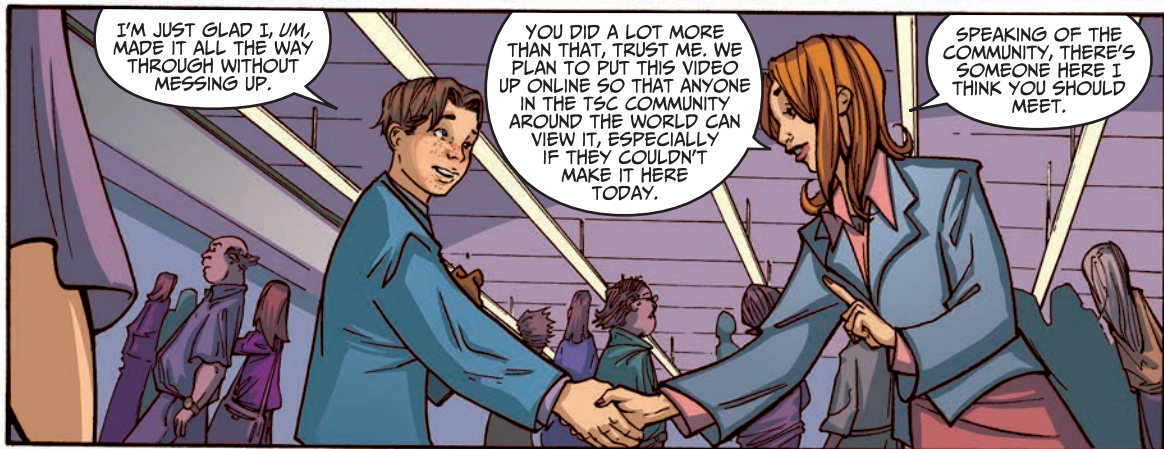
TSC FACTS

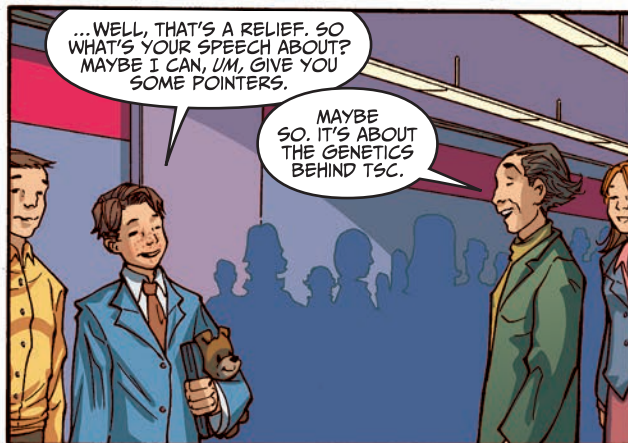
- WHILE TSC AFFECTS EACH PERSON DIFFERENTLY, MOST WITH TSC SHARE GENETIC THREADS IN COMMON.
- TODAY, THERE ARE SPECIALTY TSC CENTRES AROUND THE WORLD THAT FOCUS ON A MULTIDISCIPLINARY APPROACH TO CARE.

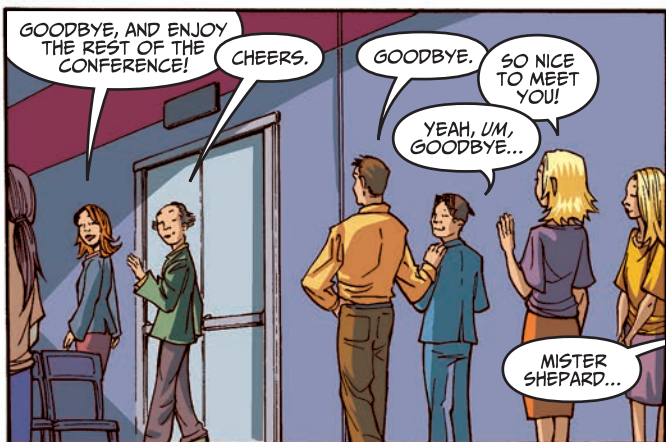
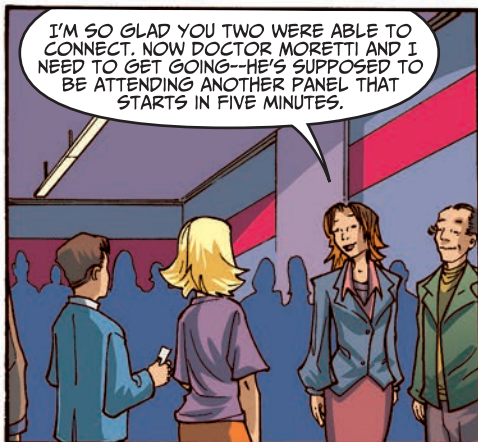
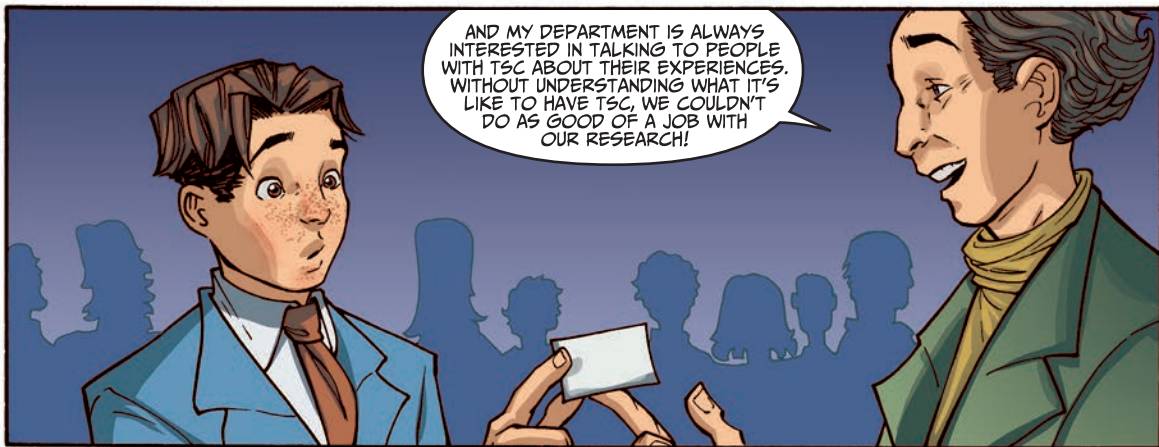


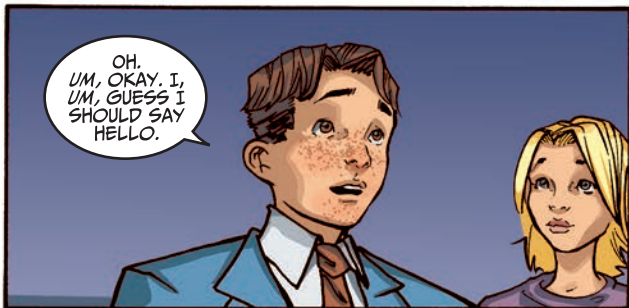
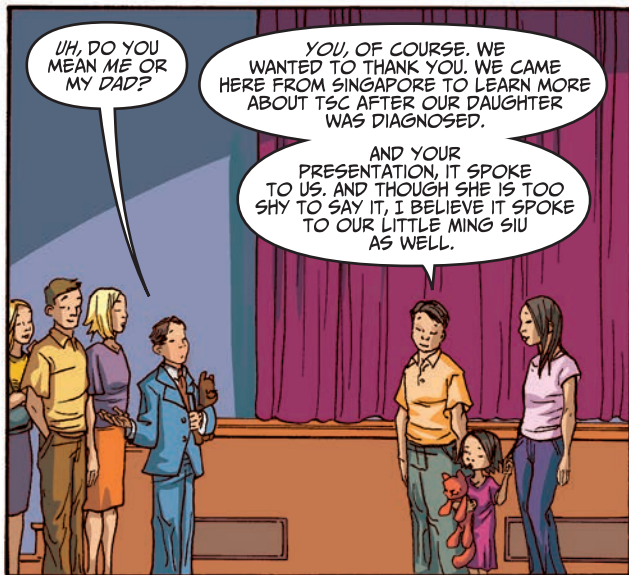
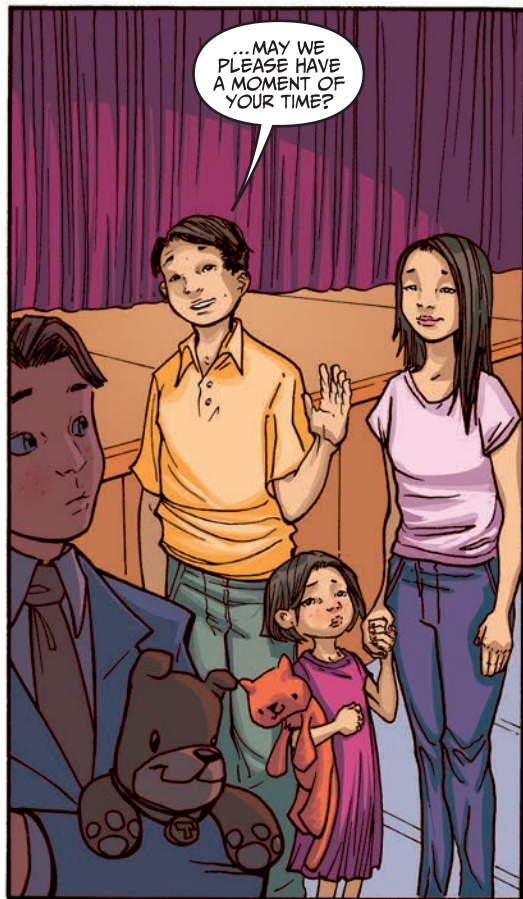


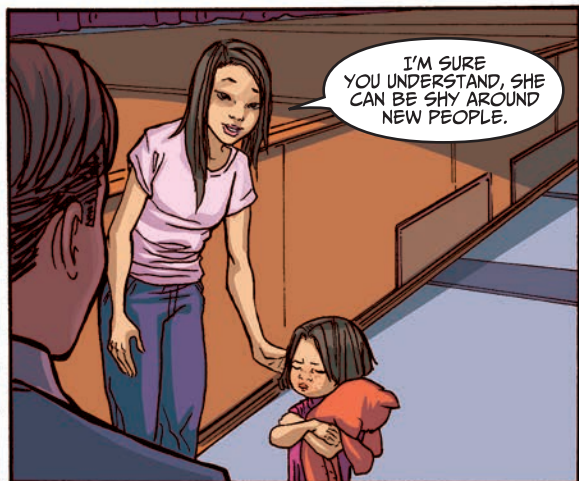
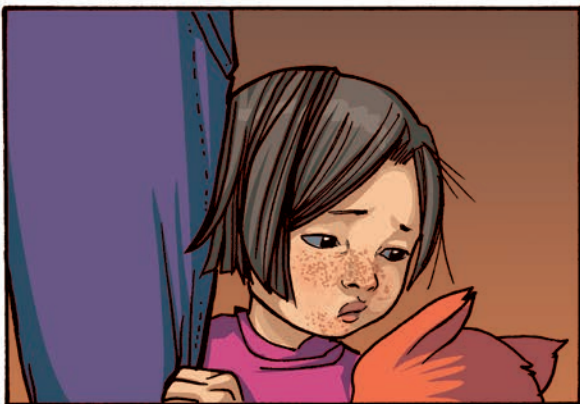
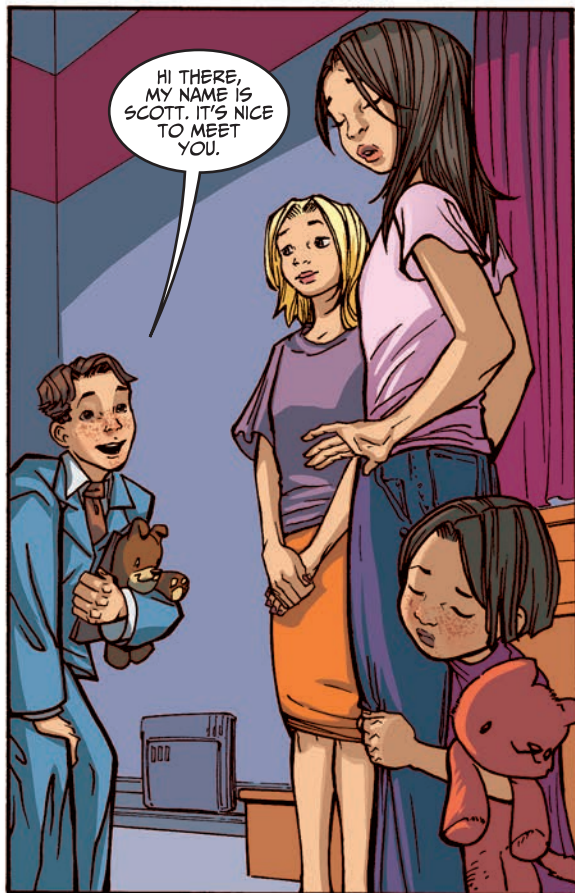


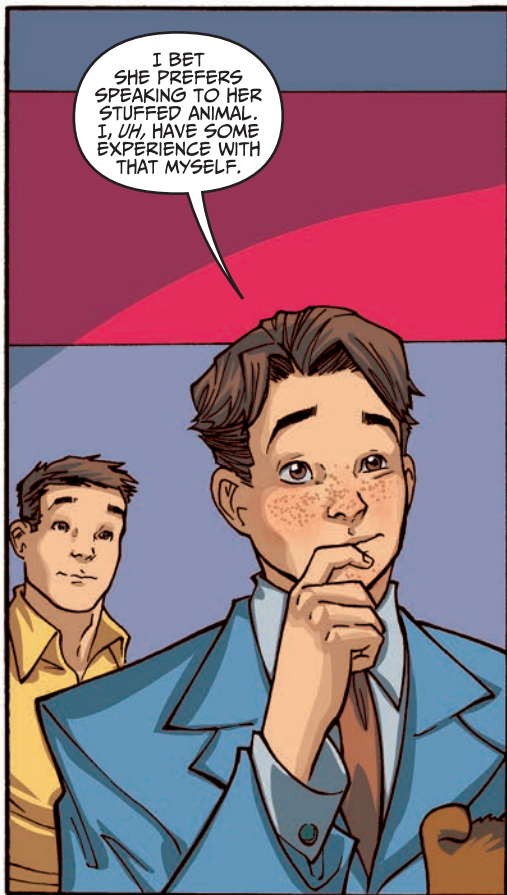


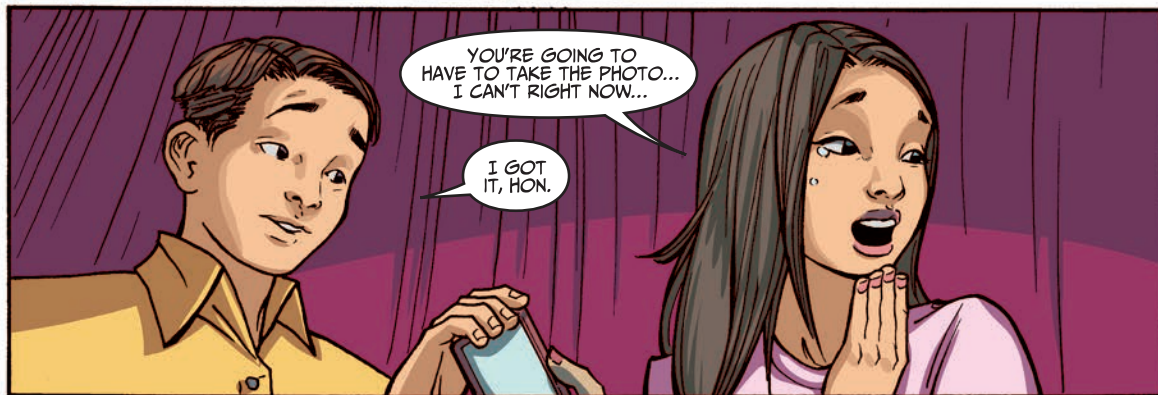
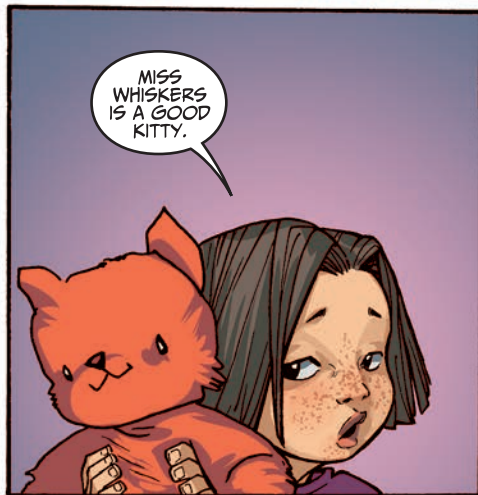






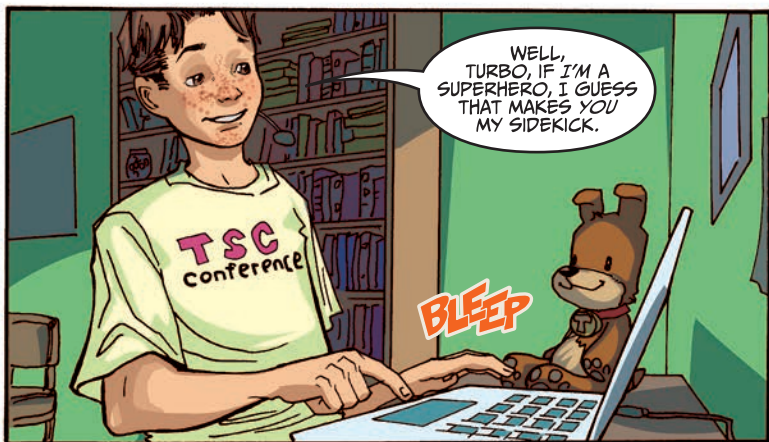














...LET'S
GET TO
IT.



scott shepard

+ Follow



Just back from the TSC Conference -
can't wait to talk about it!
#TSCsuperhero #TSCcomplex #IAMTSC
#TSCCommonThreads

**THE
END**

ACKNOWLEDGMENTS

The Turbo & Scott graphic novel would not have been possible without the support, input and insights from the global TSC community including the TS Alliance, TSC International, TS Australia, TSC Canada, the Japanese Society of TSC and the TS Association UK, as well as patients and caregivers from all over the world. The guidance of Dr. Patricia Dill, Specialist for Pediatric Neurology, FMH, and Co-President of the Swiss TSC Network, has also been invaluable.

TSC PATIENT ORGANISATIONS



Tuberous-Sclerosis.org



TSCInternational.org

Visit this website to find a local

TSC organisation near you

TURBO & SCOTT





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