

# AIB-APS PRESENTS: WORLD **BRONCHIECTASIS** DAY

## SHORT STORY

HI! I AM MARTA  
AND I AM 31  
YEARS OLD

BUT  
SOMETIMES I  
FEEL LIKE I'M  
80



## AS A CHILD, I WAS FREQUENTLY ILL



THE DOCTORS SUSPECTED THAT I HAD  
CYSTIC FIBROSIS, BUT THE TESTS WERE  
NEGATIVE



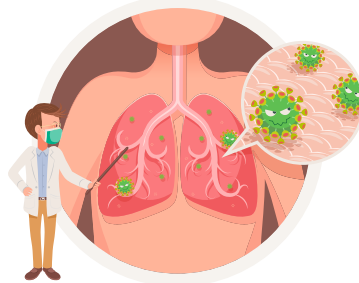
...I WAS THEN DIAGNOSED WITH ANOTHER  
DISEASE: BRONCHIECTASIS. THEY TOLD MY  
PARENTS THAT "UNFORTUNATELY, IT HAS TO  
BE HANDLED A BIT AS IT COMES."



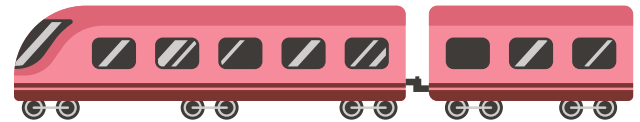
THIS IS MY MOM. SHE  
DIDN'T REALLY  
UNDERSTAND HOW TO  
PROCEED.

# WORLD BRONCHIECTASIS DAY

ANYWAY - TO MAKE IT SIMPLE - IT'S A CHRONIC LUNG DISEASE CHARACTERIZED BY IRREVERSIBLE ABNORMAL DILATATION OF THE BRONCHIAL TREE RESULTING IN RECURRENT INFECTIONS, FEVER, PERSISTENT COUGH, PNEUMONIA, FATIGUE, DYSPNEA, BLOODY MUCUS, HEMOPTYSIS AND CHEST PAIN



BASICALLY: AS SOON AS YOU WAKE UP IT FEELS LIKE A TRAIN HAS RUN OVER YOU - TWICE



YOU CAN BE BORN WITH IT OR BRONCHIECTASIS CAN COME TO YOU IN THE COURSE OF YOUR LIFE. THE CAUSES ARE VARIOUS AND THERE MAY BE ALSO OTHER RELATED DISEASES

... IF YOU ARE UNLUCKY

ON THE OTHER HAND, IF YOU ARE LUCKY AND NOTHING SHOWS ON YOUR FACE, YOU WILL OFTEN HEAR SOMEONE SAY:

...BUT YOU DON'T LOOK THAT SICK

IS THAT A COMPLIMENT?



OTHER "APHORISMS":

WHY DON'T YOU TRY YOGA?

IF YOU DON'T THINK ABOUT IT YOU'LL FEEL BETTER

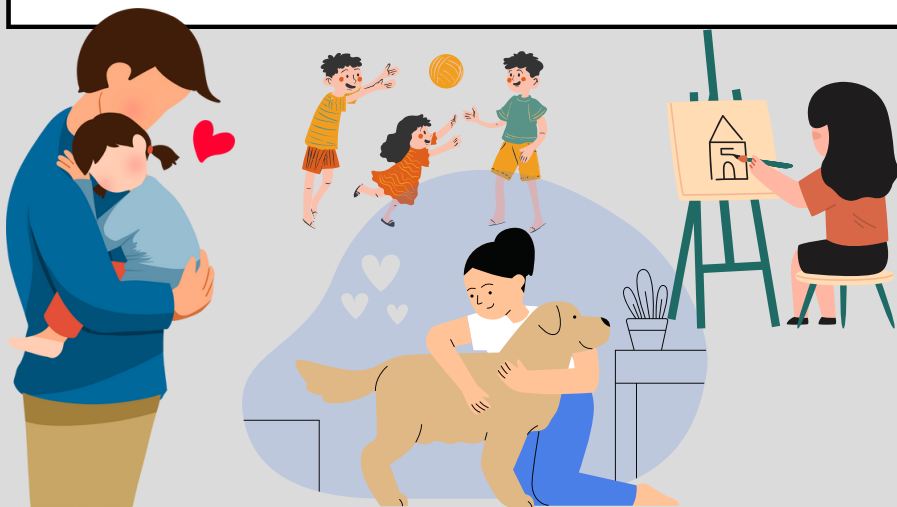
YOU SHOULD DO SOMETHING ABOUT THAT BAD COUGH

THINK POSITIVE!

# WORLD BRONCHIECTASIS DAY

## A NORMAL GIRL:

THAT'S HOW MY PARENTS TRIED TO RAISE ME.. AND THAT'S HOW I FELT FOR A WHILE



BUT SOMETIMES THIS DISEASE TOOK OVER. I'D OFTEN MISS SCHOOL, I SPENT A LOT OF TIME ALONE AWAY FROM MY FRIENDS AND MY HOBBIES



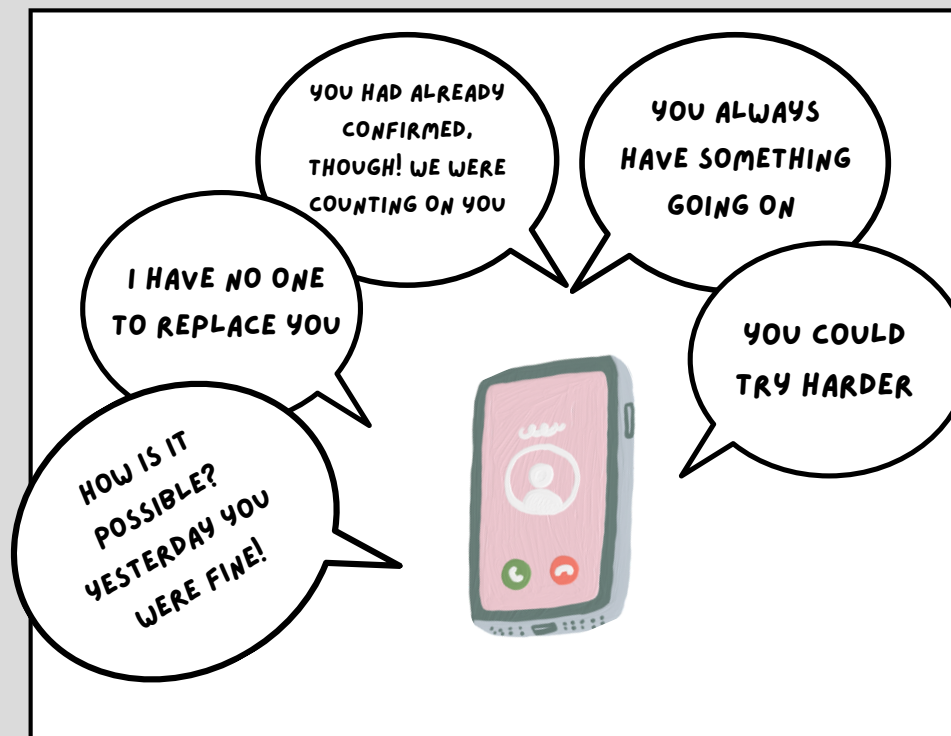
GROWING UP THE PRESSURE TO KEEP UP WITH OTHERS INCREASED. FOR THE FIRST TIME I UNDERSTOOD AND FELT THE REAL BURDEN OF BEING SICK: ANXIETY, DOUBT, FATIGUE, ANGUISH...



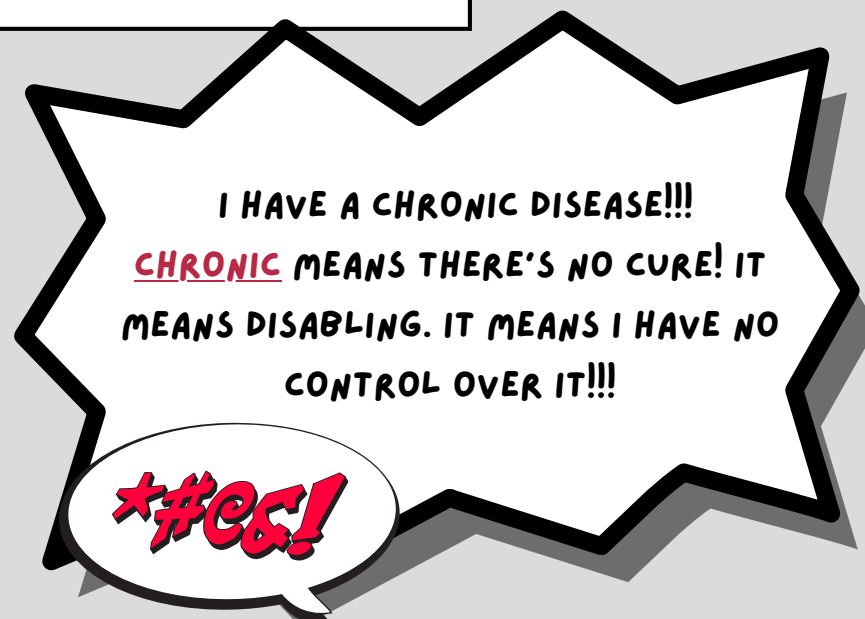
I FELT HELPLESS AND WAS DRIVING MYSELF CRAZY!



# WORLD BRONCHIECTASIS DAY



AND I WISH I COULD SAY:



# WORLD BRONCHIECTASIS DAY

FOR MANY MANY YEARS I COULDN'T FIND ANSWERS OR A SPECIALIST THAT WAS PREPARED TO TREAT THIS ILLNESS. I WAS TOLD TO HOPE FOR FUTURE RESEARCH AND A POSSIBLE TRANSPLANT.

I OFTEN FELT LIKE I DIDN'T HAVE A FUTURE

WHY SHOULD I MAKE PLANS OR COMMIT TO ANYTHING IF I ALWAYS SEE MYSELF FORCED TO GIVE UP?

BUT IT WASN'T ALL BLACK EITHER: IN THE END, I MADE IT THROUGH COLLEGE. WHILE STRUGGLING. ERASMUS AS WELL. WHILE STRUGGLING. WORKED, TRAVELED, HAD FUN, WAS HAPPY...WHILE STRUGGLING. BUT ALWAYS SUPPORTED BY THE LOVE AROUND ME



HOWEVER, UNFORTUNATELY, YOU CAN'T HEAL WITH LOVE, POSITIVITY AND HAPPINESS.

MY HEALTH SITUATION QUICKLY WORSENERD AND I HAD TO UNDERGO A SERIOUS SURGERY

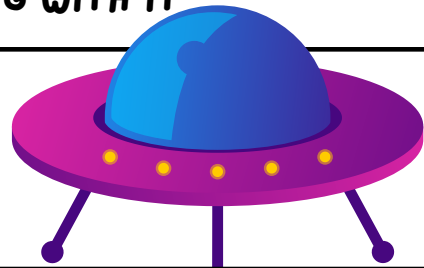


2018: PULMONARY LOBECTOMY  
IT WAS A MESS AND THE LONGEST HOSPITALIZATION OF MY LIFE. THEY TOOK OUT A PART OF MY LUNG THAT I REALLY DIDN'T GETTING ALONG WITH ANYWAY. IN THE END IT ALL WORKED OUT PRETTY WELL FOR ME.



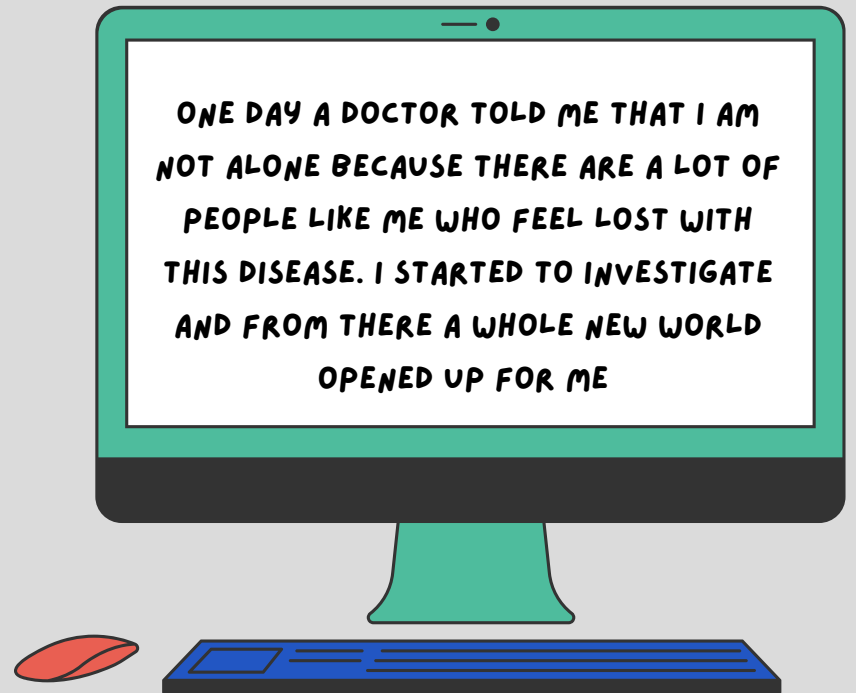
# WORLD BRONCHIECTASIS DAY

UNTIL 2019 I THOUGHT I WAS ON MY OWN,  
THAT I WAS SOME KIND OF ALIEN ON THIS  
PLANET HOLDING HANDS WITH THESE  
BACTERIA WITHOUT EVEN BEING  
RECOGNIZED AS A CHRONIC PATIENT IN THE  
HEALTH SYSTEM WITH THE BENEFITS THAT  
COME ALONG WITH IT



P.S.: I STILL DON'T HAVE THIS  
RECOGNITION

ONE DAY A DOCTOR TOLD ME THAT I AM  
NOT ALONE BECAUSE THERE ARE A LOT OF  
PEOPLE LIKE ME WHO FEEL LOST WITH  
THIS DISEASE. I STARTED TO INVESTIGATE  
AND FROM THERE A WHOLE NEW WORLD  
OPENED UP FOR ME



ALONG WITH OTHER PATIENTS WE FOUNDED  
AIB (ITALIAN BRONCHIECTASIS ASSOCIATION),  
NOW AIB-APS. WITH THE HELP OF OUR  
SCIENTIFIC COMMITTEE WE TRY TO MEET THE  
NEEDS OF PEOPLE WITH THIS PROBLEM



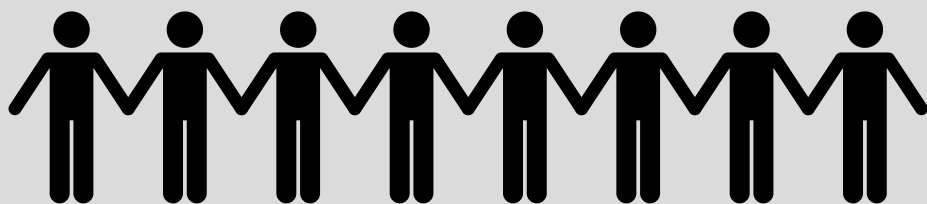
COVID MADE IT EVEN MORE CLEAR THE  
IMPORTANCE OF STANDING BY OTHERS  
AND SUPPORTING EACH OTHER. IT WAS A  
SCARY AND DIFFICULT TIME: SO MANY  
OF US WERE DEPRIVED OF CHECKUPS  
AND EXAMS.



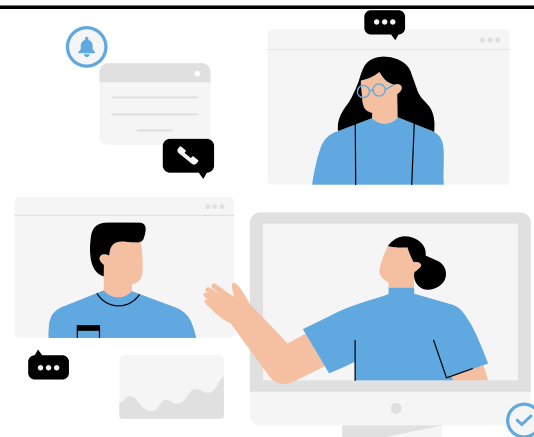


# WORLD BRONCHIECTASIS DAY

**DONATELLA, ELISABETTA,  
ROBERTA, MARIO, LUCIANA,  
MARCO... WE ARE ALL PATIENTS  
AFFECTED BY THIS DISEASE, BUT  
WITH ENTHUSIASM WE CARRY THIS  
MISSION TO GIVE VOICE TO ALL  
PATIENTS**



**WE ARE FAR FROM EACH OTHER BUT WE  
SHORTEN THE DISTANCE WITH WHATSAPPS,  
EMAILS, PHONE CALLS, MEETINGS....**



**...WHILE MANAGING THERAPY, CONSULTATIONS,  
HOSPITALIZATION, WORK, FRIENDS AND FAMILY**

**IT'S ALWAYS A PLEASURE TO BE ABLE TO MEET TO  
IMPLEMENT OUR IDEAS ON BEHALF OF PEOPLE WITH  
BRONCHIECTASIS AND THEIR FAMILIES. WE ARE  
GRATEFUL TO THOSE WHO SUPPORT US AND GIVE THEIR  
TIME FREELY, ESPECIALLY THE SCIENTIFIC COMMITTEE  
AND VOLUNTEERS.**

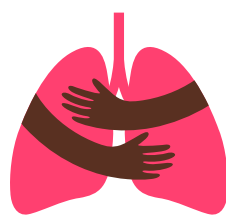


**TO DATE, THERE IS STILL LACK OF  
RIGHTS FOR PATIENTS WITH  
BRONCHIECTASIS  
AT THE LEVEL OF EXEMPTIONS AND  
DISABILITY**

**THERE ARE NOT ENOUGH DEDICATED  
BRONCHIECTASIS CENTERS AND  
RESPIRATORY PHYSIOTHERAPISTS  
THROUGHOUT ITALY, DELAYING  
DIAGNOSIS AND MAKING  
MANAGEMENT OF SYMPTOMS AND  
FLARE-UPS DIFFICULT**

# WORLD BRONCHIECTASIS DAY

**ANYWAY, LET'S GET TO  
THE CONCLUSIONS:  
WHY IS IT SO  
IMPORTANT FOR US TO  
CELEBRATE THE  
SECOND WORLD  
BRONCHIECTASIS DAY?**



**BECAUSE NO ONE SHOULD FEEL  
ALONE OR LOST AS SO MANY OF  
US HAVE FELT.**

**BECAUSE NO ONE SHOULD SEE  
THEIR SITUATION WORSEN AS  
THEY SEEK CONCRETE HELP OR  
WAIT FOR A DIAGNOSIS.**



**BECAUSE WE NEED TO BE HOPEFUL  
ABOUT THE FUTURE AND NOT  
ANXIOUS.**

**BECAUSE WE NEED TO SUPPORT  
SCIENTIFIC RESEARCH.**

**BECAUSE BRONCHIECTASIS IS STILL  
NOT TALKED ABOUT ENOUGH....**

**BUT THERE ARE SO MANY OF US!**

**SUPPORT OUR MISSION:**

**BECOME A MEMBER:  
[HTTPS://BRONCHIETTASIE.ORG/DIVENTA-  
SOCIO/](https://bronchiectasie.org/diventa-socio/)**

**HELP US BY DONATING:  
IBAN: IT46F0306909606100000170399**