



HAE

Heroes Appear Everywhere

Cecilia Ramirez

A translation of
AEH
Aprendiendo a Encontrar Héroes
Cecilia Ramirez

Living with a rare disease: hereditary angioedema

The original version was written and published in print and pdf in April 2016, using my mother tongue, Spanish, as I am from Argentina. I translated it into English.

Cecilia Ramirez. May 2017.

Prologue

What an unexpected privilege you have given me, to share these lines with your thoughts, be part of this, your story. To have Hereditary Angioedema and our Patient Association printed in your book for the posterity. Something inconceivable years ago!

Because of genetic lottery, Ceci's and my way crossed "by chance" some time ago, as both suffer from HAE. At that moment both of us had started a search: Ceci was looking for her diagnosis and I, for a tool that allowed us to go along this meandering road in a more tolerable way, opening doors to a better life.

Along this path we understood that when faced with adversity there are only two possible choices: hopelessness or fight. Ceci did not take long to choose to fight, accept, help and compromise rather than stay indifferent and this way a fulfilling life started, as you will discover on the pages of her generous testimony.

When you undergo such complex situations, nothing results as gratifying as the possibility to help others, that now immersed in this path will be able to have a different perspective to make her journey lighter and more relaxing, and above all, hopeful. Ceci gives us this testimony not thinking of her, she offers it generously as a tool to help us along our lives. I have no doubts this is the real goal of this writing.

Sharing our vulnerabilities and our personal struggle with others, trying our way to be useful for others becomes a marvelous example of "empathy", a word which is not frequently considered but so needed in the world today. To be able to put yourself in the other person's place, understand the emotional world of the other and this way, to help.

Through her personal experience, Cecilia shows the growth of that determined, optimistic and committed being that against all odds reaches her goal, which, in this case, is nothing but to have a happy fulfilling life despite the difficulties.

What you will read is not only a writing, it is a testimony of life that, undoubtedly, will leave us a beautiful learning experience. Thanks Ceci, in the name of those who got together to share this journey and today make up the Asociacion Argentina de Angioedema Hereditario. You are an example of a person who struggles. Alejandra Menendez

Acknowledgements

This writing is one more step in my search, I am a teacher of English specialized in Education Science and I am also a self-esteem practitioner, but, in this case, it was the school of life that led me to learn and want to transmit what you will find here.

Having a rare disease as HAE made my vision of life, the world and its people change. It is not easy to know who to thank or dedicate the words one writes; practically one should thank each person with whom one crosses in life because directly or indirectly each one leaves us something even though that may be to know one doesn't want to be like that person.

On this opportunity, I want to thank my parents once again, without them I wouldn't be on Earth, neither would I have had the experiences I had in life. They say your soul chooses, and mine chose them both.

I also want to thank my sister with whom I have shared my days since I was 4 years old.

Above all, I must express my gratitude to my husband whom I met around the 80's and next to whom I have gone through life since then. The being that has made sure I always have my medication and who has spent many nights awake next to me, at home or in hospital, when I suffered the consequences of having HAE. The man who let me fly free and with whom I have built a bond based on companionship and mutual respect.

Thanks to my son, Nicolas, my life, who fills me with light day after day, who gives me strength to go on when things do not go well and to whom I want to transmit the clearest and the most positive message I can, as he inherited HAE, a legacy I would have preferred not to pass on to him but, as reality took me to this place, I hope my story of personal growth helps him not to go through the things I had to undergo. He is my greatest motivation and the one who has made me feel the most unconditional and purest love of all. I expect my message to be optimistic and if some day he has to face the symptoms, I hope he can go ahead as I am learning to do so.

I will never forget my grandparents, especially Julio, who was the clearest example that one cannot change what happens but you can change how you react to it.

He didn't have HAE but other health problems, and gave me a great example not quitting or being pessimist ever. I have the greatest wealth of all: love and friendship. My chromosome may be broken, I may not produce human esterase but I have great capacity to give and receive unconditional affection.

In my search, which is not ended, I met very special people. I want to thank all the people who form and formed my working team at “CR Language School” who were and are fundamental in my professional growth and who did the work that needed to be done, when it was needed and I couldn’t.

Today, with a changed reality for the better, those times they came and sat near me on my bed to “make” me work despite how bad I felt recovers meaning as they always made me feel useful and necessary and that gave me and still gives me strength not to quit. I cannot forget my students that made me smile with their jokes when I went to teach with a swollen foot, leg, hand or arm. (I will not forget the “Hulk Teacher by parts” or “The teacher becoming a Teletubbie”). They were always respectful and their intention was to cheer me up.

At last but not because they are less important, I want to mention the people of the Asociacion Argentina de AEH, so important for my evolution when facing HAE: Alejandra: I will eternally be thankful for all you do to help others improve their life quality; Karime: I keep every message, every talk in my heart because we can talk between equals; Alejandro and Patricia: each meeting with you fills me with enthusiasm and hope, knowing that together we can achieve what we want. Teresa: it makes me happy to know you heard my advice and put that in practice. Marcela: it was very nice to be near you when you decided to be a mum despite all the ghosts and that we can see your pretty baby today. All the patients and their relatives I meet: you know you can always count on me and we share something maybe only we can understand.

HAE made me go through hard times but also led me to meet excellent and compromised people, doctors with great vocation, as well as “humane” nurses. To each of them I thank you for your work, your support and understanding.

Introduction

What I will write on these pages may not be anything new for those who have gone along the HAE way for so long, although it is true that each one makes his/her own way.

I want to share it with the deep desire to be able to help someone else.

When I decided to write this text I made a mental journey along my background and I realized that gathering theoretical and practical knowledge about HAE and adding it up to theories and practices about life, from the most ancient to the most modern ones, I changed my focus about the disease and what it represents for a person and his/her setting. Talking to a colleague, she told me that when she heard me she imagined I was like the oyster in which a grain of sand (HAE) had entered and it had become my pearl.

Today, 12 years after having been diagnosed, 33 after the first symptom, I think she is right. My life changed a lot and, despite what happened, I can say that I have learnt so much looking for a way out that perhaps I wouldn't change what happened to me if I had the chance.

I suffered for a long time, I complained and asked why me, why my son, but I think that I do not need to know the reason as I found it.

It is not about comforting myself or giving up the chase. I feel I learnt to live and value life, to see things from another perspective, and if HAE hadn't woken up maybe today I would be "surviving" instead of "living the fullest".

Every day I observe and hear healthy people complaining, attaching themselves to things that are easy to change, victimizing themselves for little things, and although each one lives emotions their own way, they do not realize the time they waste.

If I hadn't faced reality or if I had chosen to quit or sit back and do nothing, waiting for someone to do something for me, I wouldn't have learnt so much about life, death, health, sickness, love, friendship and happiness... and of course, about daily heroes, those who do not appear in movies but have battles day after day.

One day I realized that what I learnt as a teacher couldn't be separated from what I learnt as a patient. Medicine and Education have many points in common.

In psychology we studied about emotional intelligence and how it affected learning and it was inevitable to see how it influenced the health area.

Working on emotions was crucial. Knowing how my emotions interacted with my disease, essential.

I read a lot; I went to all kinds of workshops, looking for a cure, searching answers that may not have had a question. Until one day I told myself I had to stop trying to escape and learn to live with what I had to. It was not easy but today I feel I may have achieved it. I do not promise not to feel weak some time but some things are really clear and I will certainly repeat them along the text:

1. We have to accept what happens and take care of one's own quality of life.
2. We should collaborate with others because together we always achieve more and that is shown by Patient Associations around the world. Maybe one day science finds a solution; meanwhile we should focus our energy on our requests to get every patient a diagnosis and a treatment without difficulties.
3. We must remember that although we cannot change what happens to us we can transform our reaction and how we act facing it.

To be successful we need to be informed and look for a physical, psychological and spiritual balance.

Why is the book called "Heroes Appear Everywhere"?

When one has to live extreme situations hyper vigilance grows, at the beginning one lives life with so much uncertainty that it becomes very difficult to see things with clarity. You may spend whole days thinking why, what for; and as in a tale, the fantasy that a hero will come and take you out of your suffering appears. And there one remains sitting.

In tales everything seems easy but real life is another thing.

It is not about kissing frogs to see if a cute prince turns up. It is about advancing along a labyrinth that sometimes is very dark and confusing, others not so much and unlike epic stories, there is not a hero with a cape and sword but human beings who are common and go along life looking for answers.

So one day one wakes and realizes that the real heroes are each one of us and what we do with what happens to us. It is not about sitting to wait for someone to find a cure or for a miracle to change our destiny. It is about facing the rare disease with what is called resilience. Resilience, that capacity we have but we do not know until crisis come and one discovers that we can overcome physical and emotional pain as well as the fear of death. This leads you to concentrate on the positive capacities and attributes more than on the pathology you suffer.

If we look up "hero" in a dictionary, we can read: "person admired by their deeds and virtues, person who fulfills a heroic action (www.wordreference.com) but if we keep on

researching we can also read that on occasions the word “hero” is used to refer to “a person who saves others from great danger, producing a noticeable or high profile event.

I think all and each of us may be a hero in this sense, there are heroic actions that are not seen but they are made all the same. A doctor taking care of a patient after a 24-hour-duty, a mother next to her son as he recovers from an illness. Perhaps there are no cameras on, but there are many people that in their daily work display virtues and do deeds that maybe others do not recognize or understand.

In Wikipedia they mention characteristics such as “the capacity to solve riddles and problems, experimenting exile, what implies some kind of knowledge or initiation that makes them look different and with an uncommon morphology that takes them to do singular actions when they come back. It is also said that in literature there is some being that tries to get rid of the hero, and makes him face extraordinary combats from which he is not expected to come back; but the opposite always happens and the hero comes back victorious. They also say a hero must undergo different trials and other kinds of competences from which he always returns successful. They say heroes are part of the foundation of cities”.

When one faces a rare disease, life itself becomes a riddle until one gets the right doctor; the problems you never imagined stand first along the line of events that will trigger one after the other.

Sometimes, ignorance is such that it takes you so long to find the right way that although you do not leave your country as an exile, you may possibly exile at home, on the road from clinic to clinic and once you learn to deal with treatments and to face you own ghosts you may return strengthened. As regards morphology, those who suffer from HAE know that in our DNA there is a “failing” chromosome, an uncommon one; out of the ordinary, maybe it is not like the heroes in movies, but when we make the decision, we start doing singular things in our search for better health and a better quality of life.

As for those who want to get rid of the hero, maybe it is not a direct thing, but many times the system establishes so many obstacles on the road, health staff is so badly informed that there are days on which patients feel attacked; doubts about symptoms, the denial to give us our medication are frequent combats as well as those of the ones that accompany us.

Before reaching a diagnosis, so slow and difficult in some cases, and above all if there is not a medical record of the disease in your family , you go through tests and checkups that,

luckily, are overcome although that doesn't mean you don't feel pain and hopelessness at times.

In my case, I came across the Asociación Argentina de Angioedema Hereditario and its president, Alejandra Menendez, a true heroine who, one day, decided to form the Association that she presides to fight for better quality of life of the people with HAE. And even though she says that she only started it and that patients help her, those who want to collaborate with her as we can, know she is a pillar in this fight because she is always working nonstop to help us all to live a better life.

We can also read that "courage" to face life is one of the most obvious characteristics of a hero, but you couldn't call someone a hero if everything scared you or if you didn't go through any adventure.

The hero always has enough courage to face life problems and his/her own destiny. People with rare diseases know what fear is: fear of a crisis, fear of not getting the medication or enough money or a proper insurance for the medication they need, fear of their kids inheriting the disease and fear of the unpredictability they face day after day. That is the reason why they learn to live a day at a time and little by little they find the courage that they need to face the present and have some adventures on occasions. They are afraid of going far from home or not getting someone to help them if they don't feel well; other times, if they haven't found the cause of the swellings they feel afraid of being in hospital not knowing what is happening. But, little by little, and with your diagnosis in hand and the medication in your refrigerator or bag, you find the courage and risk going ahead step by step.

They say that "if after the battle the hero returns home, he doubts about the pre-established values, the social order and he can, directly or indirectly, change or break those rules to improve society". We can compare that to the time when patients get together to fight for their rights, to demand better quality of life.

Not only do patients resemble heroes, also their families as they stay by them and help them go along hard times, what shows love, patience, understanding and empathy.

And we mustn't forget the doctors who devote time to investigate and treat them; those doctors who give their cellphone number to their patients and are available 24 hours a day 7 days a week 365 days of the year, something not so common on these days when medicine seems to be one more business and patients stop being patients to become clients.

Those actors who do not rest in the search for a solution for their patients, that maybe do not appear in newspapers, magazines or on TV like celebrities but whose work is wonderful and deserves recognition.

Here, I should recognize three doctors that I know and deeply respect. Doctors: Pionetti, Fabiani and Malbran.

And besides, Dr. Dietz ,because even though he is not a HAE expert, he has been of great support for me on hard times.

Thoughts Collection

Thought 1:

Describing symptoms and experiences

Before being diagnosed, one can spend one or more days throwing up and with cramps that prevent you from moving, with nothing helping you feel better. Having swellings (edemas) in any part of the body that last for days and days, not being able to wear shoes and walk because of the pain, not being able to go out because you look like a monster or having pains that nothing reduces. Having to be absent from school, university, work, or the wedding of a loved one.

Spending time in the intensive care unit because your throat closes and no corticoid works, maybe a tracheotomy could help... or maybe not even that.

Spending years from doctor to doctor, from admission to admission, without anyone finding an answer, saying it may be allergy, nerves, intoxication, insect stings, strong hits... and you start to doubt about your mental state. And then, perhaps, you find the doctor and the lab that can diagnose you but you still have to take difficult decisions.

You learn there is only one medication that can help you in a crisis and its cost, only for episode, is higher than the minimum wage of any worker. And you start to fight with your health care provider so that they pay for it... you call many people, employees, medical auditors, you hand in documents, notes, and only if you are lucky they recognize something.

If your edemas compromise your life very often, you must decide whether to take a medication that brings about secondary effects that force you to frequent check-ups, and even so you do not feel out of danger 100%.

And you learn that if you have kids they may inherit the problem.

And having your kids checked and confirming your fear: they also possess the protein deficiency.

And even if you have the medication in your fridge, you know that when the threat of a glottis edema appears you must run to a health centre because what you need is an I.V. injection.

And despite having the medication, that becomes your life insurance, each time you get sick you must be on the alert because your glottis may close at any time... and when in doubt, the doctor says, you should get the medication before it is too late.

And you go to the dentist and you know you may have an edema.

And you go to the otorhinolaryngologist and he wants you check your vocal folds, or to the gastroenterologist and he wants to have an endoscopy made and you know you run risks of swelling... and you can't imagine how it feels if they want to operate on you.

And those who do not suffer like you say to you: "you shouldn't worry or exaggerate" but they forget it is not easy to live with a genetic deficiency.

Little by little you accept or try to accept what you have to live with but your children also have it and you wonder why a thousand times.

There may be times in which you have to make it clear that it isn't contagious.

You learn that someone with the same problem didn't get to hospital on time or that he/she didn't know what rare disease he/she had or this person didn't have the protein because he didn't have enough money and.... This person is gone.

And your kids get sick and you spend whole nights awake taking care of them thinking he can have a glottis edema.

Or they want to go to sleep at a friend's house or go to an excursion and your soul fills with fear but you know you can't be there with them for ever...

And one day you see an episode of Dr House, which deals with strange cases, and there appears a couple that has the same rare disease, and although the episode is not really precise, you feel happy because you think: "maybe, this way someone else will hear about it and another life can be saved or someone can be helped somehow".

Most of the doctors you go to see because of other things still don't know about the disease, and if you get to an emergency room you are the one who has to tell them what to do, and even so, sometimes they don't understand, they waste time or they feel afraid and even if the injected protein has acted, they leave you in hospital for hours, just in case.

On the way you may lose some friend because they may think you "dramatize", because when the crisis is gone nothing shows you deficiency of protein so if they aren't there when the swelling occurs, they don't understand anything, some feel pity for you, others try to understand and support you: these become your human angels. They drive you to hospital; they listen to you when you feel down.

Family, friends, maybe some workmate support you.

But, we need more... because not everyone has enough money to afford the protein, not everyone has a medical service, not everyone has support.

We need to go on researching.

We need to go on developing new medication that doesn't require an intravenous injection and that isn't so expensive.

We need to investigate to see if this can be cured or prevented in the next generation.

We need to spread information about the disease in emergency rooms in every health centre.

We need more doctors that know about the topic.

We need our health care providers to cover the expenses.

We need the Ministry of Health to get involved and collaborate.

Everyone can have a silent disease and need someone to add a grain of sand in the fight for improving life quality

Thought 2:

Rare diseases and their lessons

There isn't one, or two, neither three Rare or infrequent Diseases, there are thousands and each patient must have a unique story to tell.

The CI Inhibitor Disease or Hereditary Angioedema is not the rarest disease or the most terrible or difficult, I know there are others that are worse and more painful but HAE is the one I got and until not so long ago I didn't know why or what for.

But, following the road I had to, I learned that I had to stop asking myself "why" and say "why not"? And "what for" is becoming clearer each day.

One day, I heard Steve Jobs saying that "the dots can't be connected looking forward but backwards" and today, I look back and recognize that the way I had to follow was not easy but each instant I lived led me to take conscious decisions and take responsibility for them, to know that I am the only person who is responsible for my life, how I face my genetic deficiency and what I do to improve the quality of my life.

Looking for answers to questions I may not remember now, I opened my mind and read about everything, to try ideas that were presented to me.

I researched from scientific things to metaphysical ones, finding value in almost all of them. As I always say, I didn't find "miraculous recipes", I did not find "magical cures" but I have gone a long and very interesting way so far.

Maybe some of the things that were good for me aren't good for others, maybe I believed in things that others can consider false, but, truth is that, after 20 years without knowing what was going on in my body, from the first episode until I got my diagnosis and after the ten years that took me to accept and learn to live with HAE, each thing I learned made my mind open in a way that taught me to feel real empathy for others, to understand what others need, respect them and feel the genuine urge to help.

The strongest lessons had to do with the development of my Emotional Intelligence, with changing habits to find the positive side even in the darkest moments and never lose faith and hope.

The worst part was to clearly recognize false people, the ones that simulate to feel empathy or affection, but at the time of truth, are simply not available.

Today I wonder if this road I followed would have been the same without suffering from the symptoms of HAE. From a very young age I had curiosity about many things, but really, not finding answers, first to what my body was telling me, and then trying to know why, made me read hundreds of books and take the decision to spend time and money on going to seminars, workshops and sessions by people who marked my spiritual path.

I became a self-esteem practitioner with Rober Reasoner, I approached Non Violent Communication with Marshall Rosenberg, I learned about spiritual laws and the power of meditation with Deepak Chopra and later, and for more than 10 years I have been practicing yoga with my dear friend and teacher, Shubhankar Kumar.

I also went to listen to the Dalai Lama to talk about peace, Chamalu about happiness, Veronica de Andres about Confidence; I learned about biotypes and Ayurvedic medicine with Dr Marina Puertolas.

I followed homeopathy with Drs Gaggero and Dr Arenzo.

I learned about past lives with Dr Brian Weiss, Laura Szmuch made me work on my fears though coaching, I took different reiki levels with Marcela Riggio.

While other people complained about their lives or what they had to live, I tried to learn, and perhaps, as I heard in one of Chamalu`s talks, I passed from being asleep to be a “seeker” and then an “apprentice”.

From that perspective, I believe I still need to work a lot to become a “warrior”, but I know I am a good “fighter”.

During years I heard people say they didn`t have time, money, strength or will to sit to listen to the messages others had to give. Maybe I was ready, because despite all my work, being a mum, wife and daughter, I could always organize my time, get the money and find the strength and will that were needed. And I never stopped fulfilling my obligations or enjoying my free time.

That`s why I tell everyone: YOU CAN, stop living in the deficit paradigm and start living in abundance.

Only compromising with yourself can you find the way.

I will never get tired of saying that the two most important lessons are: firstly, to take responsibility for what happens to you. Secondly, happiness is possible.

We can`t live complaining about what life makes us face, we must use that energy trying to learn to change.

Thought 3

Feelings and Emotions

I think the worst part is when we don`t know what happens to us. With endless external and internal swellings, hundreds of visits to doctors and dozens of hospital admissions getting opinions from doctors that know nothing about the problem, maybe not because of lack of study but because they really teach too little about rare diseases at University, one starts feeling as a “strange bug”: alone, anxious, desperately searching for someone who tells us what happens to us and why and also what we can do to stop suffering.

The worst part is when nobody can understand us even if they try; sometimes nothing they say is useful, there are processes that go deep, although I can`t deny that the love around us

is of vital importance. Self – esteem is challenged by this new “enemy”, as I believe that, at least at a point in our lives, we see the disease as an enemy or a punishment.

Then, after a long time, (at least in my case) you reach your diagnosis, what for some heartless doctors seem to be the solution and final point of the problem, but, things aren't easy either. It takes time and a lot of work on emotions to recover or find emotional balance.

The psychiatrist Elizabeth Kubler Ross speaks about 5 stages of mourning of those who face a catastrophic loss or a terminal disease. Although HAE and many other rare diseases are not terminal, they are considered catastrophic, as they have low occurrence and high costs and I believe we can trace a parallel with the proposed model. These 5 stages go from negation, anger, negotiation, depression, until one reaches acceptance. She says that not everyone goes through the 5 or in that order and I don't disagree.

When one learns a little more; (and I want to be clear on this: each patient must be responsible for knowing more about his/her pathology), you learn to understand your body and you give up hoping for magic solutions that come from outside, you realize that that enemy or punishment was not such, and if you approach it with respect, it can become a great teacher.

One feels everything is over, that the end is near and one can fall into a great depression and even think that one doesn't love oneself any more, that God abandoned you. You are overwhelmed by whys and what fors which will perhaps never have an answer.

I know about people who stopped working studying and only went on with antidepressants and anxiety medication. But, if you breathe deeply and look inside yourself you may see the light at the end of the mental labyrinth.

That light that makes you trust the power of life, in that energy that can be called with the name you want, according to the religion you were raised in.

It takes time, but you mustn't quit, life seemed a straight road but became a labyrinth, but I'm sure that you find the way out; therefore, you must never stop trying to advance.

Learning about emotions is very useful, your body suffers changes when it feels them through the neurotransmitters that are liberated in your blood, and so if you manage to

equilibrate emotions, you also manage to equilibrate what happens in your body. I'm not going to write about healing but balance.

The famous Doctor Bach, who is well-known for his treatments made with flowers, said that we "were given our disease to speed our evolution", for him that was the answer. I am not going to say he is completely right, I'm just going to say that a disease appears because we must learn something, and when we have to face it, staying in the comfort zone is not correct. To say: "I can't because I'm sick", or "And what am I going to do"? are not phrases to should be pronounced by our mouths.

I know there isn't a miraculous recipe to overcome toxic emotions generated by being sick or by knowing one has a disease even though its symptoms don't appear; each one should find the way.

Some may choose to do therapy; others do something that relaxes them. What I am certain of is that you should leave the vicious circle of destructive emotions because you are not only unable to solve the health problem but also you start feeling such mental suffering that adds other diseases and each day becomes worse.

Instead, if you manage to concentrate your energy on positive aspects, on finding solutions and not focusing on the bad side, in adding up and not subtract, little by little you learn to live with what happens to you without letting this be an obstacle to fix personal and professional goals and enjoy life.

Thought 4

Self Esteem: A key which opens doors

Along my readings and courses that had to do with my professional life, I read the books written by Nathaniel Branden and the articles and books written by one of my trainers whom I admired a lot, Robert Reasoner (International Council for Self Esteem).

Maybe at the moment I decided to explore that theme, I did it to see how I could improve certain aspects in my English classes, how I could help my students, adolescents and adults, but I discovered that there was much more and that everything could be applied to my life and help me to face HAE the best possible way.

Nathaniel Branden defines self-esteem as “the trust in our ability to think, face basic challenges in life, in our right to succeed and be happy; the feeling of being respected, worthy, to reach our moral principles and enjoy the fruit of our efforts”.

When you are told you have an incurable disease, when the consequence of that little genetic deficiency has made you spend more hours of your life in hospitals and seeing doctors than in cinemas or with friends, thinking of another thing is not easy; believing that you can cope with the basic challenges in life is not easy, either; but if we are convinced that we have the right to be happy, little by little with the adequate help, we can find the way back home.

It is indispensable to see our necessities, identify our lacks, and above all, take control of what is happening, if we stay waiting for answers, we may not see that the clock goes on ticking and we can waste too much time.

Branden signals 6 pillars for self esteem; I name them here and tell you how I tried to work on myself and what was happening to me.

Awareness: it is necessary to know we are not the disease and be able to detect what defines us as a person beyond our genetic disease, we must be completely aware, as this great author says, of the decisions we take, the efforts we make and our habits, as all of them define us.

Acceptance: recognizing our feelings and emotions, the positive and negative ones, those which produce us pleasure and the ones that hurt us, accept them without being ashamed by them or afraid of them.

The disease is there, whether you see it or feel it or not. If we live in fear, it can finish with us. If we deny it we can forget to do whatever must be done so that what affects us does it as little as possible.

Accepting it is the most direct way of starting to look for solutions or at least, better life quality.

Responsibility: I insist on the idea of remembering we are responsible for what we do and decide the way we approach the problem, for how much we are willing to get out our comfort zone and direct ourselves into an improvement process.

Frequently, I have heard people complaining for not getting the medication but they have not talked to a lawyer or approached the patients associations looking for support; I have also read messages or heard testimonies of people who lived terrible moments to be injected the medication in the middle of a crisis and they were derived because doctors didn't know about the disease or simply out of apathy.

I got tired of going through unfair situations and with the help of the people of Asociacion Argentina de Angioedema Hereditaria I learned to self infuse the medication I need when I have a crisis and I can't get a nurse or doctor willing to help me.

Respect towards others, the doctors that know little or the ones who know a lot but cannot empathize with us and mainly, respect for ourselves and our necessities.

Sometimes this failed DNA makes us lose our self-respect and love and that doesn't take you anywhere.

Purpose: I believe the fundamental purpose is to heal or at least improve our life quality. It is necessary to establish long and short term goals and be clear about which actions will take us to reach them; call them: medical treatments, therapy, patient support groups; remembering that together we are stronger.

Through what happened to me, I discovered my purpose in life: To help others whether they suffer from HAE or not

It is great to see what happens each time I deliver a workshop or seminar or if I talk to someone with some difficulty.

I feel the "flow" of which Csikszentmihalyi speaks about, and I know I can be happy despite the obstacles my health presented me with.

Integrity: to try to find congruence between what we say and what we do. If we really want to feel better, we must do what we need to do.

I know there are difficult moments in which we feel tired and defeated, but it is always good to align what we feel, think, say and do for our health and in other aspects of our life as, obviously, feeling well in other aspects of our lives favors our health.

Thought 5:

Solidarity: it belongs to everyone. Rare disease day (March 1st 2015 after an event about rare diseases)

Today I reflect, as usual, or a little more. What Steven Hawking said comes to my mind “the survival of the human race depends on goodness and cooperation”

I feel a mix of emotions: on the one hand, I feel gratitude towards all those who yesterday said I'm here to support what I wanted, to accompany the association of patients and relatives with rare diseases on its worldwide day.

We need to become visible so that public policies are implemented so that the laws that will help hundreds or thousands of people find diagnosis, treatment and life quality, apart from the inclusion of this topic in the subjects of the medical career.

I felt the love of relatives, friends, ex school classmates who said “here we are with you Ceci!” and they may not know how happy they made me.

I know they could have chosen to go sightseeing around that beautiful place, looking at beautiful things, but they chose to wear the white t-shirt, the violet ribbon and give me or the whole society two hours of their lives, where they didn't see people complain or cry because of what they have to face, they saw people together claiming for their rights in a pacific way, getting together despite the different things they have to face. People supporting each other. Hugs, smiles, colors, photos, music. People passing by asked what we were giving, the answer could have been: “the best we have: solidarity; and we celebrate being alive”.

Absences of certain persons who preferred to look another direction but forget that anyone can have a rare disease and not know. Sometimes life faces you with unexpected things, whether it is a rare disease or another kind.

Maybe for the press the topic was not as important as what color someone's dress was, so they didn't give us some minutes to cover the event.

They forget that rare diseases are not contagious, that as they are genetic or autoimmune, the only ones that can inherit them are our children and that is what makes us stronger and fight even more. To say present has a deeper meaning and maybe it's beyond many people's understanding.

To feel empathy is so necessary in our society!

But I will not stay on the negative side, what for?

I will keep in my heart the gratitude of different patient associations, above all the one I belong to: AEH Argentina with its “coach” (as one day someone called her) Alejandra Menendez.

I keep the kisses and hugs of those who have been walking close to each other, with the photos saying “we need a team”, with the solidarity of some famous people who gave some minutes of their time to take a photo supporting us and uploading that in their social networks. With the ones who announced the event on their web pages, with the media that said something about the topic.

I know the bitter taste of the absences will go away in a few days and I keep all the people who said “here I am”.

Thought 6

Ten Tips for Emotional Intelligence when there is a disease. * Ten “Cs” (in Spanish)

After years researching about emotional intelligence related to education, I could also see the relationship with health.

I summarize what I feel and confirm that help me balance in 10 tips:

- Knowing your motivations
- Considering our lights & shadows
- Capacity for cooperation
- Pacific Communication
- Health care
- Contemplation of Nature
- Contemplation of Nature
- Connection to our soul
- Trust in our own resources
- Understanding the intra & interpersonal Intelligences
- Managing emotion-action.

Emotions are not good or bad. They are there and we must recognize them.

Depending on how we deal with them, we can feel better even when symptoms visit us.

And our emotional intelligence will evolve, be weakened or get stuck.

We need in order to achieve its evolution, to concentrate on the following, step by step.

- **Knowing our Motivations:** If you know where you want to go, it is easier to go along the way. You need resilience, overcoming obstacles, jumping barriers, without being in a hurry but without stopping. If we know what motivates us it is easier to go along our labyrinths.

Who are you: you or the disease?

- **Considering our lights and shadows:** When we consider them, we will know what we should go on nurturing and what we should change. To know our virtues is important, without any vanity but with clarity. To recognize our defects to watch them and little by little change them in essential.

What strengths can you use when you face a crisis? Which weaknesses can you transform?

- **Capacity for Cooperation:** Man wasn't born to be alone, he needs others. Sometimes it is not easy to forget our own egos and remember that we are all part of the same history, we all want the same ending. Competition doesn't generate anything good; criticizing, either. Only cooperating do we achieve real results. How willing are you to devote part of your time to help people with some rare disease as yours or another?

Which will be your grain of sand?

- **Pacific communication:** Words leave their own vibration. As when meditating we use mantras that attract positive micro vita to our energy, choosing the right words wisely can help to avoid unnecessary conflicts. Not to lie, not to be quiet, to communicate efficiently is possible. To avoid the ambiguities is vital. The same as listening; we must pay attention because we sometimes do not hear what the other wants to say.

Are you ready to claim for your rights as a patient?

Can you ask doctors or scientists for the information that you need correctly?

- Health care: Without health, all is in danger. Remembering a healthy diet, exercise and basic care are necessary and fundamental. Emotions are influenced by all that today is part of Psychoneuroimmunology. All is part of great “holos”, interconnected.

Do you run away from checkups or become responsible for taking care of your own health? Do you get advice about your disease, the treatment & secondary effects?

Do you help your treatment with a healthy diet and exercise?

- Contemplating Nature: It is the best example of harmony, simplicity and excellence.

Do you have time to connect to nature and help your brain get into “alpha” (state of relaxed alertness)?

- Connecting to your soul: It is in it where mind and heart get together. It is the Soul the one which really knows which the purpose we brought to this existence is and there are people who say that diseases come so that you find it easily. I can't state or deny this, but I feel it is when we are connected with our soul that we really feel fulfilled. When we feel sad or unsatisfied we are moving away from it.

Have you ever thought we are more than a body?

- Trusting you own resources: Everyone, absolutely everyone, has the tools to overcome problems, to be responsible for our acts, feelings, emotions and reactions.

Which are your resources?

What are you willing to do to enhance them?

- Understanding your inter & intrapersonal intelligences: Being aware of who we are is the first step, to learn to relate to others is the second.

How much do you know yourself?

Do you know which of you internal states affect your symptoms? How do you relate with others when you have symptoms; and when you feel good?

- **Managing Emotion-Action:** Once we can know what we feel, give our emotions a name, which is clear & precise as well as others' emotions, we can handle them to act towards fulfilling our objectives.

Do you know how your emotions affect you HAE?

What are you willing to do to recognize, understand, express and regulate what you feel in the face of HAE and contribute with you biopsychospiritual well-being?

It is never too late. You can always give one more step towards the right destination. Little by little you realize that heroes appear everywhere

This is only my humble testimony so far.

Go for it and find you own heroes. You can. And when that happens everything becomes simpler, happier and you start believing in happy endings.

Thought 7

Once I wrote this to have it at hand if I felt down: "If your heart beats, if you can get up in the morning, if you breathe, if you do what must be done may not be really living, you may be surviving... to live you must feel, you must know who you are, which your lights and shadows are and accept yourself, and above all you must know which the purpose of your life is.

If you know that, you have taken a step forward, you still have many others to give... it all depends on your choice of LIVING or SURVIVING.

To really live you must abandon your comfort zone and take risks; you must accept the things you must face and have faith thinking there will be something good out of it

The fact that there are no coincidences, that everything is part of the big quantum soup of causalities should be kept in mind

The people you cross along your life, the obstacles, and the trials you have to face...

To live you must be present in every single moment and leave the autopilot off so that you don't get lost.

To go where you want to go and not where others want you to go or make you believe you must go.

Remember Einstein once said “There is a kind of strength more powerful than steam, electricity and nuclear energy: it is human willingness”, and do not ever forget that for many years you had a phrase painted at the entrance of your institute saying “If there is a will, there is a way.”

i ALEJANDRO MALBRÁN 1, 2, DIEGO S. FERNÁNDEZ ROMERO1-3, ALEJANDRA MENÉNDEZ4
ANGIOEDEMA HEREDITARIO GUÍA DE TRATAMIENTO El angioedema hereditario (HAE) es una enfermedad rara, autosómica dominante, caracterizada por episodios que comprometen la piel, el tracto gastrointestinal y la laringe. Tiene una mortalidad histórica por asfixia del 15 al 50%. Es producida por la deficiencia funcional del C1 inhibidor. La identificación de la bradiquinina como mediador principal ha estimulado el desarrollo de nuevos medicamentos para tratar la enfermedad. El tratamiento del HAE se establece en consensos internacionales. ii http://www.businessballs.com/elisabeth_keubler_ross_five_stages_of_grief.htm
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