Live Beyond Epilepsy: *Be Inspired*

The Inspiring Experiences of People Living with Epilepsy

Foreword

You're about to meet some inspiring people. They come from around the world and they all have epilepsy – the most common serious brain disorder.

In words and pictures they will tell you about their lives, their hopes, their challenges and their dreams. Most of all, they want people to know them for who they are, not for their epilepsy.

50 million people around the world are living with epilepsy. Some were born with epilepsy, others have developed it following an injury or illness. They have seizures which are caused by excessive electrical activity in the nerve cells of their brain. Their seizures range from mild to severe, occasional to frequent.

Many of us within the epilepsy community have seen important advances in understanding and treatment of epilepsy. But we still have a long way to go before everyone with epilepsy can live without fear of prejudice, with the freedom to live their dreams.

By sharing the experiences in this booklet, we hope to encourage more people to move towards a better future and to live beyond their epilepsy.

Dr. Kenneth Saké
Associate Director,
Global Medical Affairs, UCB

Susanne Lund

Susanne Lund
President,
International Bureu for Epilepsy

Introduction to
Live Beyond Epilepsy

***Live Beyond Epilepsy** is an epilepsy awareness and education initiative from UCB. It brings together a series of innovative programmes designed to improve the lives of people with epilepsy, those who live with them and those who care for them. The campaign aims to:*

- **empower people living with epilepsy to take control**
- **encourage physicians to see their patients beyond epilepsy and in the context of their life needs and dreams**
- **look to the future to improve the perceptions and understanding of epilepsy for the next generation**

To support its aims of raising awareness and improving public and medical understanding of epilepsy, Live Beyond Epilepsy provides educational materials to healthcare professionals and people with epilepsy.

By enabling people with epilepsy to learn from others' experiences in different countries and cultures, Live Beyond Epilepsy seeks to inspire people to achieve their goals.

By allowing people with epilepsy to describe how they have taken control of their lives, Live Beyond Epilepsy gives them a platform to share their personal message with a worldwide audience.

This is Hanna

Hanna is a law student in Germany. She speaks thoughtfully and confidently, and smiles easily. She is looking forward to starting work when she has finished her studies, and she plans to travel, especially to Latin America whose culture she is passionate about.

Until recently, Hanna spent a lot of time asking why, from the age of two, she has had epilepsy. Why it was she who was teased at school. Why it was she who was different. Why it was she who had to take her epilepsy medicine. Why, when she tried to cut down her medicines in the hope that her epilepsy had gone, it was she who had a major seizure at a lecture, in front of 300 other law students.

'Eventually, I realised that I needed to shift the focus outside myself - to move from “why do I have epilepsy?” to “how can I enjoy life with epilepsy and how am I going to fulfil my dreams?”, ' Hanna explains.

'I decided to get to know my epilepsy. I've learned to accept and respect certain boundaries, like going to bed before 12 o'clock if I don't want to feel dizzy and dreary the next day, and taking my medicine. But within those boundaries, I can move freely. I can study law which I love, I can play tennis with my Dad (and beat him sometimes!), and I can drive my car. In the future, I hope to be a mother and to have a daughter so I can have the kind of special relationship that I have with my mother.

'I don't know why I have epilepsy or why that man over there doesn't. However, I do know how to live with epilepsy and that the practical knowledge I have about my epilepsy is essential to my happiness.'

> ***‘Eventually, I realised that I needed to shift the focus outside myself – to move from “why do I have epilepsy?” to “how can I enjoy life with epilepsy”...’***

This is Laurens

Three years ago, Laurens made the momentous decision to undergo brain surgery for the third time, to try to control his epilepsy. He did it for his small son, Jesse, whom Laurens and his wife, Judith, had recently adopted from America.

> ***'Our new life started the day I left hospital. To celebrate, we adopted our second child Ishan, and I can now lift my children, play with them, swim and drive my car, and work in a job I really enjoy.'***

'Due to the number of seizures I was having, I could not risk lifting Jesse. But my wish to be able to carry him was the spur to investigate my options,' Laurens explains.

His epilepsy was the result of falling onto a spike which pierced his brain, on his eighth birthday. An operation stopped the bleeding in his brain but, through much of his childhood and early adult life, Laurens had multiple, severe seizures each day. At last, a second operation when he was 19 enabled him to be seizure free for four years:

'At 22, I lived independently for the first time. It was amazing doing things for myself and making my own decisions. I worked hard, earned my own money and I felt that I counted,' Laurens recalls.

But his seizure freedom didn't last and, despite the joy of meeting and marrying Judith, who also had epilepsy, Laurens felt completely rejected when he lost his job because of his frequent seizures. Determined not to be beaten, he retrained as a carer for the disabled, earning his diploma, despite being forced to stop his training three times because of his seizures.

Laurens believes that it was his positive attitude that convinced surgeons to perform a more specialised, two-part operation to find and treat the origin of his seizures. The surgery was a success and, combined with appropriate treatment finally gave Laurens the control he valued so much:

'Our new life started the day I left hospital. To celebrate, we adopted our second child Ishan, and I can now lift my children, play with them, swim and drive my car, and work in a job I really enjoy.'

'We may look like a typical family doing typical things. But to us, each day is a gift and every "mundane" activity is a miracle!'

www.freedominmind.com

Introduction to
Freedom in Mind

Freedom in Mind is an artistic project, a joint initiative of UCB and the International Bureau for Epilepsy, which calls upon people with epilepsy to express what freedom from seizures means to them. Through pictures, poems, readings, music and films, those who take part are providing important insights into the effects of epilepsy on their daily lives.

They are showing that, for them, freedom means being independent and going places on their own, playing football, getting a good job, making friends, falling in love. It means no longer living in fear of the unknown, but being able to come out of the shadows and feel the sun, to be at peace.

Those who are contributing to Freedom in Mind do not want our sympathy and they are not full of self pity. They want to live positively with epilepsy and to be treated as equals.

Selected entries are being included in a unique multi-media exhibition, called the Freedom in Mind Experience which is touring international medical congresses throughout the year.

We hope that the Freedom in Mind Experience will provoke new thinking about what seizure freedom means to people with epilepsy and encourage improvements in dialogue.

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Pictures opposite, left to right: ***Fall*** *– Allison, US •* ***A Beautiful Windmill During Foulness [Bad] Weather in Holland*** *– Jitka, Czech Republic*
A Stroll Through the Forest *– David, New Zealand •* ***Relaxing Against the Water*** *– Jane, Denmark*

Silke, Germany

Help with Life from Experienced Epilepsy Patients to Newly Diagnosed Patients

Freedom from seizures means to me new freedom to my life, personal freedom without fear of a seizure. No seizures means new self-confidence, it means to be able to live with a happier frame of mind, no seizures means to be able to push forward to new personal limits and take on new burdens. To stand up in a new manner. It simply means a better quality of life. To live without seizures. My pictures are supposed to express my new feeling for life and my new confidence.

Zak (Age 2), UK

A Colourful Crab

I am blind and have very little limb control but I like the feel of paint. I have constant seizure activity affecting my left arm. I would love to be free of seizures so that I can have more control of my artwork. In my painting this shows as the smoothness of the right side and the jerkiness of the left side.

(Written by Zak's mother. Zak has since died, but his creative spirit lives on through his pictures).

Audrey, Ireland

'Freedom to Me'

It's finding the strength from within my soul
To break free from these chains
It's peeling away the outer layers
And seeing what remains

It's getting behind the wheel of a car
Going places on my own
Journeying deep inside
Without playing prisoner to the phone

It's staying up all night
Without keeping an eye on the time
It's taking back the childhood gifts
All that's rightfully mine

It's rock climbing and abseiling
It's free falling through the sky
It's getting through the dark days
Without questioning why

It's recapturing those lost years
When I was young and free
It's revisiting the one I was
Before this monster came to me

It's falling in love with someone
Without the fear of what they'll say
If and when they hear my secret
If it will mean they'll walk away

It's not living with a shadow
A burning in your brain
It's not living with self pity
And why I'm not the same

It's not hearing nagging voices
About sleep and work and drink
It's having the chance for independence
It's having space to think

These are the things that I envisage
The colours that I see
The goals I wish were close at hand
The ones I cannot see

But I am who I am
And though sometimes I'm not free
That's just fine because
Without it I would not be me

Danuse, Czech Republic

The Storm

I have been completing drawings for the last 32 years. I am drawing during my seizures too. I also draw by ink into glass – only when I am seizure free. When I am sad I draw by oil colours or I do aquarelles
Extract only

Kim, Canada

'The Missing Piece'

Blank stare, a brick wall
Logic is gone out the window
Completely not there

Memory shattered
Into many tiny pieces
A puzzle unsolved

Dazed, confused, perplexed
Unaware of consciousness
Location unknown

Scared of unknown things
Seized into an existence
No one understands.

Hide for protection
Embarrassed of reality
Pretend 'normalcy.'

Want the missing piece
To feel normal again
A complete puzzle

Want freedom to be
Completely independent
Of my own doing

Fate dealt something else
A strange hand I accepted
The power to teach

To educate one
Equals the empowerment
Crumbling dense walls.

I do as I please
Independent of a piece
Living life my way

Stefano, Italy

I would like the darkness to leave me alone

In my drawing, I've shown two ostriches which represent the times before and after treatment. That's why I'm proud to live in a rich country with the right medicines.

Introduction to

Living with Epilepsy: freedom to be...

*'**Living with Epilepsy: freedom to be...**' tells the stories of a group of inspiring women and men in the USA who aren't letting their epilepsy get in the way of leading happy and fulfilling lives. They go to school or college, have interesting jobs, play sports, and have fun with family and friends.*

> ***'The turning point in understanding Rachel's diagnosis was when a doctor told me 'You need to look at how to manage epilepsy, not cure it.'...***
>
> *Rachel's Mum*

Their lives are described through a collection of compelling photographs and descriptions which capture a typical day for each of them.

Those who took part in the project are passionate about the need for better public understanding about epilepsy. They are eager to share their lives in order to dispel the misconceptions which surround epilepsy. They want to show that they are living life on their own terms and they aren't letting epilepsy stand in their way.

The 'Living with Epilepsy: freedom to be…' exhibition is sponsored by UCB, Inc. Displayed as a series of 48 panels, hung as floating walls, in US epilepsy clinics and hospitals, and at conferences, the exhibition is putting a face on epilepsy which the public hasn't seen before.

Pictures opposite, top left to top right: Monica, Rachel

This is Rachel

'I give thanks every day for my daughter's spirit and her determination that allow her to achieve so much...'

Rachel has had epilepsy since she had a stroke when she was just six weeks old. But she has never let it take over her life or make her depressed. Instead, she has always laughed and played just like other children. She loves riding her bike and joins in sports with her brothers and sisters.

By showing that she can have the same happy, active childhood as other children, Rachel has opened people's eyes and hearts to living beyond epilepsy. She is helping to change the way people think about epilepsy and how they act towards those who have the disorder.

It hasn't always been easy and, at first, Rachel's Mum and Dad were afraid that Rachel wouldn't be able to have a 'normal' life because of her epilepsy.

But it wasn't long before they realized that nothing was going to stop Rachel from leading a happy life, playing with her friends, going to school and making her own way in the world.

This is Monica

> **'I go on living every day. I paint, I bake, even dance on a good day. Life isn't for standing still, no matter what cards you're dealt.'**

Monica's epilepsy is the result of a brain tumour, diagnosed when she was 32. The tumour was successfully treated, but the seizures came as a shock at first. She decided not to hide her epilepsy from her friends and family, and was determined that it wouldn't take over her life.

Thanks to her love of dancing, Monica rediscovered an inner strength which has helped her deal with the ups and downs of her epilepsy. She paints, goes to yoga, meets up with her friends, and travels on the Manhattan subway on her own when she needs to.

When Monica moved to America from Venezuela where she was born and grew up, Monica dreamed of opening her own bakery. She's always been creative and, today, some of that creativity goes into baking elaborate cakes for all occasions.

Wish for the future

'To grow old and to be able to say when one is old that life was wonderful in spite of epilepsy.'

Manfred, Germany

live Beyond Epilepsy

*UCB is committed to enhancing the lives
of people with epilepsy, their families and carers,
and is working to create greater awareness
and understanding of epilepsy.*

www.ucb-group.com
www.freedominmind.com