CTCL … in our own words

CTCL is Cutaneous T-cell Lymphoma. It is a rare cancer, prevalent in both women and men across Europe, that causes skin disease in the form of patches, plaques, tumours and overall redness, and can also affect the blood, lymph nodes and internal organs.

It is not easily diagnosed. So many people with CTCL live through long periods of their lives in severe discomfort with a low quality-of-life, and without a diagnosis, access to effective treatment or knowing they have a cancer that is usually not curable, so could shorten their lifespan.

To help understand and share what life with CTCL is like, three people living with this condition offered to share their stories with us.

This is CTCL … in their own words.

Kyowa KIRIN

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Foreword

This report highlights the experiences of three individuals diagnosed with cutaneous lymphoma (CL),* a rare cancer that crosses dermatology and haematology. Living with a diagnosis of CL is often challenging and, for many people, hard to come to terms with. The experience can be isolating and lonely. Patients documenting in their own words what it is honestly like living with this rare disease is an important step forward to understanding the gaps in care that need to be addressed.

For those not familiar with CL, the real-life experiences shared here clearly illustrate the frustration that is part of many individuals' CL journeys. We at the Cutaneous Lymphoma Foundation know that much of their discomfort can be reduced if they, and their clinicians, have better access to useful information. Knowledge empowers patients.

The stories shared in this report highlight the importance of connecting people and their families with others who live with CL. Very few cases of CL exist, so it is a real challenge to connect this micro-community across languages and countries, both for patient organisations and affected people. The Norwegian interviewee sees the benefit of relating to others but explains that he is one of only 20 people nationally with this condition. This will not deter us as the Cutaneous Lymphoma Foundation has seen first-hand what a difference it makes for people and their families to become part of a broader patient community.

Working together as a global cutaneous lymphoma community, we can find pathways to support those impacted by this condition: creating innovative solutions for people to find the most appropriate treatments; help them connect with cutaneous lymphoma specialists in their country; and connecting them with other patients/carers. Those living with this cancer will see that they are not alone and, wherever they are, help is nearby.

The key to better outcomes for those with CL lies in today's science and technology innovations. But this is only part of the picture. Rare conditions such as CL are too often invisible to the medical community.

* Cutaneous lymphomas are classified into two main groups – T-cell or B-cell.[1] This document focuses on two subtypes of Cutaneous 'T-cell' Lymphoma – mycosis fungoides and Sezary syndrome.

Many clinicians are not aware of CL, and consequently don't see that some chronic skin problems may potentially be a rare cancer. This needs to change so patients can be diagnosed earlier and receive the right treatment.

Today's CL situation in many countries reveals a lack of understanding by clinicians about emerging research and new treatments. In this light, an essential goal for patient advocates is to ensure that every clinician who treats CL patients is aware of the specialist resources available to them. For example, the EORTC-Cutaneous Lymphoma Task Force and the International Society of Cutaneous Lymphomas provide excellent professional resources for clinicians at all knowledge levels. These platforms are a game-changer for improved CL diagnosis and treatment. They enable the sharing of new clinical and research information. They can also give non-specialist clinicians rapid access to the world-class knowledge of global CL experts.

There is much work to do that can only be done through a collaborative effort. The Cutaneous Lymphoma Foundation, and the global community of patients and families it serves, believes it is essential to begin a dialogue. Listening to the day-to-day challenges of people with CL can be heart-breaking. At the same time, engaging in dialogues like this brings hope to people worldwide, who feel lost and alone, giving them a place where they feel supported and connected.

Susan Thornton
Chief Executive Officer
Cutaneous Lymphoma Foundation
www.clfoundation.org

Why this report?

This Patient Experiences Report was created by Kyowa Kirin International (KKI) to raise awareness of Cutaneous T-cell Lymphoma (CTCL) and demonstrate how it affects the everyday lives of people who live with this condition.

In the interview section, three people living with CTCL tell us their stories. The sections describing the CTCL condition and ways forward are compiled by KKI, as a result of the interviews and from existing background materials referenced in the report.

Our special thanks to Susan Thornton, Chief Executive Officer of the Cutaneous Lymphoma Foundation, who shares her insights in the foreword to this report; and to Ellie, Frédéric and Al for sharing their stories with us.

The content and ideas presented in the interview section are the opinions of the interviewees alone; these comments do not necessarily reflect the views or policies of KKI or its employees.

Living with Cutaneous T-cell Lymphoma (CTCL)

Imagine that tomorrow you are suddenly bothered by **painful and itching skin.** Day and night. Your physician prescribes creams that reduce the discomfort, but it keeps flaring up.

You see a dermatologist, who prescribes stronger cream medication. The situation improves temporarily. But over time it becomes much worse – more itching and dull pain, many sleepless nights. During the worst flare-ups, you prefer to stay at home as **the appearance of your skin is embarrassing,** and the general **discomfort makes you apathetic and less interested in your work and socialising with friends.**

Nothing seems to calm your situation. Your dermatologist keeps investigating, and you may be referred to other doctors. After some months – or years – the bombshell drops … your worst fears are realised and you are diagnosed with the 'Big C' … **a rare blood cancer called Cutaneous T-cell Lymphoma (CTCL). It's a form of lymphoma that manifests itself on the skin.**

CTCL can be managed and maintained once the optimal treatment is identified. This takes more time. And depending on the type of CTCL you have, and other personal factors, an effective treatment can be identified. But this too can change. So, the search for effective treatment continues – as your CTCL condition fluctuates between better and worse moments.

You now have clarity on your situation. Your CTCL journey starts here.

This scenario summarises the lives of women and men across Europe who live with CTCL today. **CTCL is often mistaken for psoriasis, eczema** or related skin conditions. **Typically, it is not rapidly diagnosed as it affects small numbers of people.** There is **little knowledge about this condition among the front-line physicians** who people with CTCL initially consult – family doctors, general practitioners and dermatologists.

Overleaf, you will meet three individuals, from the UK, France and Norway, currently living with CTCL who have agreed to share their stories with us, in the hope that these perspectives will improve the understanding of what CTCL is – and how care and support for people living with this condition can be improved.

These are the stories of three people living with CTCL Ellie, Frédéric and Al … in their own words.

Ellie

UK

With CTCL, you live your life in 'good' and 'less good' moments.

My advice to doctors is to treat people living with CTCL in one centre to avoid sending them to different specialists in different locations. My journey has been difficult because it has been so disjointed.

In case you're not familiar with CTCL, this is how I can describe it.
CTCL has two parts: it's a blood malfunction that manifests itself on my skin. It looks like psoriasis on a bad day. It feels like having flu and really sore skin at the same time. At this point people usually say: 'I bet that's awful …' People sometimes say: '… your skin looks sore. How does it feel.' I explain: '… have you ever had a carpet burn or bad scrape? Imagine a paper cut and how irritating that is … but it's on your entire body.'

My journey: My skin problems started in 2004 and were diagnosed in 2010.
My first skin problems started in 2004. I was diagnosed with CTCL in 2010 and started receiving care from my current consultant in 2014. This means that I was in a grey area for nearly ten years. For my first four years with this condition, my doctors were listening, but no one really investigated what it was. My doctor prescribed topical creams, but no one made the connection that it might be something else – even when my skin was plaquing and showing CTCL symptoms. As CTCL is not a common condition, no one really asked: 'I wonder if this is something else …'

My diagnosis: For several years I was treated for psoriasis and eczema.
For a few years I had skin conditions which were treated as psoriasis and eczema. Then I was also separately diagnosed with another form of cancer, Hodgkins, and treated for this with chemotherapy. Coincidentally, during this treatment, my skin condition cleared up. When my skin discomfort reappeared later, I consulted my GP who saw that this may be more than a typical skin condition. I was referred to a consultant dermatologist and that's when I was diagnosed with CTCL. I am now treated by a medical team with a lead consultant who links to several specialists. Together they help manage my condition.

To be honest, I felt confused when I was diagnosed.
They called my condition 'mycosis fungoides'. I asked what that was. The dermatologist explained: 'it's a form of cancer … it's not in your skin, but in your blood'. That totally confused me; I couldn't make the connection to what he was saying. I kept seeing a dermatologist and it wasn't until a long time after, when I started with my consultant who treats me now, that I understood that I have a rare cancer called CTCL. For the first few years I didn't really know how to talk about it. When you have CTCL, there's no CTCL-specific patient group to connect with, the awareness is not there; the 'big cancers' take the limelight.

They said: 'we don't know where our CTCL information is … we've never had to use it.'
In the medical centre where I was first diagnosed, they told me: 'we have information about CTCL, but we don't know where it is, because we've never had to give it out'. So, my husband and I decided to look up details of CTCL ourselves.

My journey
(7 + years to diagnosis)

2004, symptoms began

2004-2008, treated with topical creams for skin problems

2008-2009, also diagnosed with Hodgkin's lymphoma; treated with chemotherapy and radio therapy

2008-2009, chemotherapy cleared skin; doctor suspected this was more than 'skin problems'

2010, diagnosed with mycosis fungoides/CTCL

If you search the national cancer group websites for CTCL, they offer no information on the condition. They cover blood and skin cancer but not CTCL. This is why I agreed to share my story with you. I can't think of any other way that CTCL can become better known. There's no big CTCL campaign. Nobody is saying what research is happening. I don't know of any CTCL-specific groups.

With CTCL you live your life in good and less good moments.
My CTCL has different stages. If I am having an 'episode' where my skin feels really bad, this affects my life massively due to pain and 'presentation' – how my skin looks to others. I love swimming and go four times a week. But at certain times I can't, for two reasons: 1) I can't bear the presentation of it in public, and 2) during these times it makes my skin very sore. This affects my physical and emotional wellbeing and I have periods of feeling incredibly low and apathetic.

In my current treatment cycle the situation has become bad. But I know that I will start to feel well at the end of the treatment, so am thinking about that. This gives me hope.

What keeps me going is the hope that I will get through the situation and get back to more normality in my life. For me, normality is to be able to pursue the interests that I have, to wear what I want … with CTCL, what you wear is an issue; you can't wear clothes that irritate the skin.

My husband is my primary support.
He is a Formulations Chemist and we did a lot of research together on the CTCL condition. My consultant dermatologist has been absolutely key to helping change my life – both in addressing CTCL and in my ability to take control.

My life is fantastic in every other area. I will not be defined by this condition. I have really supportive family and friends, and my work colleagues are understanding and accommodating. With this support I think I am well-placed, compared to others that have CTCL. When I am not in pain, CTCL is a part of my life that I put in a box and put to one side.

"With CTCL you live your life in 'good' and 'less good' moments. That's how I think. In my treatment cycle, when my situation is bad, I look to the end of the cycle; this gives me hope. Today I know that with my current treatment, I will start to feel well in the near future. That's what I'm thinking about now."

2010-2019, tried many treatments; adverse reaction to some so tried others – radiotherapy, electron beam therapy, spot welding, UV light box

2019, team managing my condition: lead consultant and several specialists; now approaching my last available treatment options

CTCL FAST FACTS

DIAGNOSIS

Diagnosing CTCL is a lengthy process for many people with the condition.

They typically live between two and seven years with CTCL symptoms before having a confirmed diagnosis.[2] This is because these conditions are seen simply by medical professionals as eczema and psoriasis, especially in the less advanced stages of the disease.[1]

CTCL IN EUROPE

1 in 110,000 – 1 in 350,000[3] – estimated number of people affected by mycosis fungoides
1 in 10 million[4] – annual incidence of Sézary syndrome
1,790 – number of new cases of both conditions diagnosed in EU 28 countries (2013 study)[5]

Frédéric

France

My CTCL diagnosis was rapid … but I still lived through nine months of severe discomfort.

It's confusing sometimes. To know that this is an incurable condition, and that people think that you are cured because you've returned to work. But this kind of auto-immune condition can reoccur any day.

My CTCL was diagnosed by skin biopsy and blood analysis.
My problem emerged in 2017 and CTCL was identified later that year. Yes, it was a relatively rapid diagnosis, but I lived through nine months of severe discomfort before the condition was identified.

I developed severe skin problems – very uncomfortable red plaques. Not knowing what this was, my doctor did imaging and blood analysis tests that showed no real results. Concerned about my situation, my doctor sent me to the local university hospital where the internal medicine specialist diagnosed my condition as CTCL. I am lucky: the Professor leading my medical team specialises in CTCL and knows the condition well.

If you're not familiar with CTCL, here's what it's like on a typical day.
CTCL takes away all my energy; it eats me from the inside. I have severe attacks of itching and discomfort. But you won't see it. People with CTCL don't necessarily look ill. Generally we do not show visible issues, such as hair loss from chemotherapy, loss of appetite or weight.

Before I was diagnosed, I had lost all comfort in my life.
I no longer slept, my skin itched constantly. I was incapable of doing professional or intellectual work. It impacted our relationship as a couple. I no longer wanted to do anything. I had no energy and huge tiredness. The constant itching further damaged my skin. The beginning of the condition was very violent – this was nine months of my life. I was focused on myself, at a time when I really needed to be open to the world around me in search for more comfort. But that wasn't possible.

When I was diagnosed, my doctors didn't say the word 'cancer' outright.
Then I wondered 'why do I have this?' It's difficult to accept that you have such a disease; your world collapses. But you can't give up and have to keep going forward.

The mistake I made – that I would not recommend – is to go to the Internet. I think the best approach is to see your doctor and ask them many questions such as: 'what does my future look like?' It's important that I have this information, as CTCL is an incurable condition. But it's one that we can manage and push back.

My discussion with the medical team is important. A number of treatments are now available to slow

My journey:
(1 year to diagnosis)

August 2017, severe skin problems; very uncomfortable red plaques

September 2017, doctor did standard tests – imaging and blood analysis … no results

December 2017, sent to university hospital; diagnosed with CTCL

Since December 2017, now followed by hospital professor and team

the progress of CTCL. In the future I think treatments will emerge that can stop it. My current cycle is a treatment every 10 days (blood exchange), which is quite heavy.

Since my treatment started in late 2018, my life changed enormously.
With my immunotherapy treatment, I could sleep again and was no longer continually uncomfortable. I could resume small tasks around the house without stopping due to exhaustion. Today I still have CTCL symptoms, but they are less acute.

I am now back in contact with friends, have a normal social life, go out, and have friends at home. I would now like to return to work. I asked my medical team if I can work. They said not just yet … but soon.

It's confusing sometimes. To know that this is an incurable condition and that people may think if you return to work, you are cured. But this kind of auto-immune condition can reoccur any day.

How can doctors identify CTCL more quickly and precisely?
Diagnosing CTCL is complicated, as each form of lymphoma is different. Doing blood analysis together with skin biopsy helps look at the situation in detail to pinpoint the problem effectively.

My big regret is that I am not linked to a support group of people with CTCL. In my case, we are a small group being treated by the same professor, with the same therapies. But there is no connection between us. It is a shame that we are not part of the medical team's multi-disciplinary meetings. There is a local group for melanoma but not specifically for us.

I am in the web forum France Lymphome Espoir (France Lymphoma Hope) where I exchange with others on our experiences of living with CTCL. Generally, I think that it would be useful for CTCL to be more explicitly included in lymphoma forums and discussions.

"My big regret is that I am not linked to a support group with others who are also living with CTCL. Where I am treated, we are a small group of people, followed by the same professor, receiving the same therapies; but we are not connected. It also is a shame that we are not part of the medical team's multi-disciplinary meetings."

My wife was an incredible help, along with our kids and friends.
I think CTCL impacts the spouse of someone who has this condition, more than anyone else. Of course, the medical team provides continual support, but family and friends are there for the day-to-day. My treatment is at a university hospital. I am followed by a professor and his team of interns that changes every six months.

CTCL FAST FACTS

QUALITY OF LIFE & LONG-TERM SURVIVAL

In the period before they are diagnosed and can access effective treatment, people with CTCL conditions live with a poor quality of life.[6]

Early diagnosis is key to ensuring the comfort of people with the condition and effectively managing CTCL.

If CTCL progresses to later stages, the prognosis can worsen. Most people diagnosed with early-stage CTCL do not progress to more severe conditions. At advanced stages, only 50% of the patients with mycosis fungoides and Sézary syndrome survive for five years.[7]

CTCL CONDITIONS

CTCL incidence increases with age.

Most people are diagnosed with the symptoms of CTCL at 50-80 years old. Men are twice as likely to develop it.[8,9] When diagnosed at an early stage, CTCL conditions do not progress to a more severe stage for most people affected.[10]

Al

Norway

My experience gives me insight into the kinds of support that can benefit others living with CTCL. I wish there were support groups.

It was ten years before I was diagnosed with CTCL. Doctors initially said I had seborrheic dermatitis, psoriasis and eczema, and there was no mention of cancer.

I went to dermatologists and had allergy tests, but had no idea that cancer was a possibility.
I was put on anti-itch and corticosteroid ointments that were gradually increased in strength by my doctor. I was tested for allergens, which showed that I was allergic to dust. The problem continued on-and-off over the years. At one time I shaved my head due to sores and an itchy scalp.

In 2010, my wife noticed a little scar on my thigh and asked about it. I told her that it was nothing to worry about; just a little lump that healed by itself. Two years later (2012), she saw a new lump twice the size, next to the initial scar. We consulted a dermatologist. The biopsy revealed divergence from normal cells. Again, I was treated with corticosteroid and advised to watch my skin more closely and return if it happens again. There was no mention it could actually be a form of cancer.

In 2013, I got a reddish, irregular, immovable lump on my left forearm. It did not change in size and appearance, and I had a biopsy in 2014. I continued going to work but was getting tired easily. In March of that year, my wife and I saw an oncologist and a dermatologist where we were informed that I have a CTCL type called mycosis fungoides.

We found the diagnosis situation for CTCL quite confusing.
The family was in shock when they learned I had cancer. My wife read extensively about CTCL, learning from testimonials of people living with CTCL and clinical trials on the Internet. Our social life was put on hold. It took a while before we told our friends that I have cancer.

When I was finally diagnosed, my doctors presented the treatment possibilities available to me.
These were interferon, chemotherapy, radiation, immunotherapy, photochemotherapy and stem cell transplant – and the resulting adverse effects.

Some personal reflections on my diagnosis:
I was all alone when my doctor informed me that I had cancer. I felt very sad and wish my wife or our son had been with me. When the doctor explained my condition, he made sure that I understood what he was saying - asking me several times if I understood what he meant.

My journey:
(8 years to diagnosis)

2007, had skin problems, diagnosed as seborrheic dermatitis, psoriasis, eczema; treated with corticosteroid ointments

2010, noticed scar on my thigh

2012, new lump appeared; saw a dermatologist. The biopsy showed cell divergence; treated with corticosteroid. No mention that it might be cancer

2013, reddish lump on my left forearm

2014, had a biopsy, saw an oncologist and dermatologist; we were informed that I have CTCL or mycosis fungoides

2014-2015, several treatments - Interferon injections, chemotherapy combinations; no improvement

My advice to others with undetermined skin disorders:

- Don't give up until you find the right diagnosis.
- Seek help from specialists, for CTCL this means dermatologist and oncologist.
- Pray for healing.
- Have an open relationship with your family.
- Stay positive.
- Keep your courage in battling the difficulties that come up along the way, even when your situation seems hopeless.
- Live your life as if you don`t have an illness.

My doctors put me on several treatments which did not help improve my situation. These included Interferon injections and several courses of chemotherapy. With special permission from the Ministry of Health, I had access to a drug from the US that is not registered in Norway. From the day I took this medication, my tumours began to change towards healing, slowly but surely. This drug paved the way for a stem cell transplant that I had in 2016. Today I am in remission and stable health, with some radiation therapy for minor problems.

I wish there were CTCL support groups. But as this is a rare disease, that affects some 20 people in all of Norway, contacting others in this community is problematic; we don't know of any CTCL groups here and are looking for one. There are community groups for people receiving treatments for lymphoma, but not for CTCL.

I thank the government of Norway and my loving wife for her strong support. We are thankful to be in Norway where we are not hampered by healthcare costs. Many thanks also to the doctors who have closely monitored my condition over the years.

Our life is stable for the moment. After this difficult journey, I am happy to say that the main events for us over the past three years have been several happy family holidays, with my wife, sons and granddaughter in some beautiful and relaxing places!

"My advice to others with undetermined skin disorders: Don't give up until you find the right diagnosis; seek help from specialists; pray for healing; have an open relationship with your family; stay positive; be courageous, even when things seem hopeless; live life as if you don`t have an illness."

2015, had access to a US drug, not registered in Norway; tumours started to heal

2016, stem cell transplant

2019, in remission and stable health for three years; some radiation therapy for minor problems

CTCL FAST FACTS

IMPACT ON PEOPLE & SOCIETY

CTCL deteriorates the quality of life for those who live with it. It has a severe impact on daily functioning and social interactions for these people:

1. Skin can be disfigured, itchy, painful and unpredictable, causing lack of sleep.[6]
2. Mental health and emotional status can fluctuate, including feelings of depression, frustration, embarrassment and fatigue.[11]
3. People feel they are missing out on their social life; CTCL can affect their relations with those they love.[11]

CTCL also has a broader social impact:

4. It affects people's ability to meet their families' needs.[11]
5. It interferes with work life, for example, resulting in missed days.[11]

TREATMENT

Today, CTCL is treatable but not curable. The most common treatments for less advanced CTCL stages are skin-directed therapies:[1]

- **Topical corticosteroids (steroids)** – These treatments work well, but after several months' people living with CTCL may fail to adequately respond to them.[12]
- **Radiation therapy** is very effective for people with limited tumours. It provides immense relief for uncomfortable lesions, but the use of this type of therapy decreasing, as are other high-dose radiation treatments.[13]
- **Internal whole body, 'systemic' therapies, such as chemotherapy** are used in late-stage CTCL treatment.[1]

TAKING A STEP FORWARD FOR CTCL CARE

People living with CTCL hold the key to better care.

As a rare condition, CTCL brings specific challenges to those who are affected, society, our communities and families. Everyone who is part of a CTCL journey can help improve the situation for people living with the condition today.

What will make this a reality?
Better sharing and learning: between people with CTCL and their peers; between patients and the medical community; and between dermatologists,' general practitioners and oncologists.

That this rich knowledge can help improve the lives of all those living with CTCL.

The experiences that were shared here by Ellie, Frederic and Al shed new light on the hidden world of CTCL and those it touches. Their stories teach us that CTCL is very different from many cancers, or skin and blood problems.

Making life better for the CTCL community across Europe needs fresh thinking and new approaches.

What will help?
Better information and education for all those involved: With the small community of people living with CTCL and its difficult-to-diagnose symptoms, new approaches that spark learning and deepen education on this condition will benefit all those involved: the CTCL community and their families, dermatologists, family doctors and general practitioners, oncologists, healthcare providers and support staff. What's needed?

Suggestions include:

- **Doctors can connect their patients (with consent)**, who may seek a CTCL community
- **People with CTCL can share their experiences** and diagnosis journeys with doctors who don't know CTCL
- **Patient organisations** that address broader cancer topics such as melanoma, skin cancers and lymphoma can consider how to include more explicit CTCL information and expertise into these groups

Tapping the unique real-world expertise of people with CTCL: CTCL is not widely-known in the mainstream healthcare community. This means that people living with it are often the experts on aspects of CTCL diagnosis, care needs and choices.

People in the CTCL community have a wealth of practical information to share. They can contribute their real-world expertise to CTCL groups and the medical community. Especially to general practitioners and dermatologists – typically the first contact point for people that may have CTCL.

Key questions: clear information for faster diagnosis and better CTCL treatment

- **How can we raise the profile of CTCL** among dermatologists and general practitioners, so they have the consideration to ask: '… maybe this problem is something else?'
- **How can we encourage medical teams with CTCL expertise to share their knowledge** with their peers, to speed precise diagnosis of CTCL conditions in their communities; involve people living with CTCL in work of medical teams, and connect patients they are treating into 'mini-communities'?

- **How can we better share the deep knowledge of the CTCL community** with medical professionals, healthcare staff, patient groups and caregivers? In many cases, people that have CTCL are the experts on approaches to care and quality of life decisions.
- **How can we** embed patients' expertise into larger, well-staffed groups such as the, melanoma and lymphoma communities?

In many ways, patients' unique knowledge of CTCL holds the key to faster and more precise diagnosis, most appropriate treatments, and more comfortable care.

KEY PATIENT CONTACTS & RESOURCES

- Lymphoma Coalition Europe
  https://www.lymphomacoalition.org/europe
- Cutaneous Lymphoma Foundation
  https://www.clfoundation.org/

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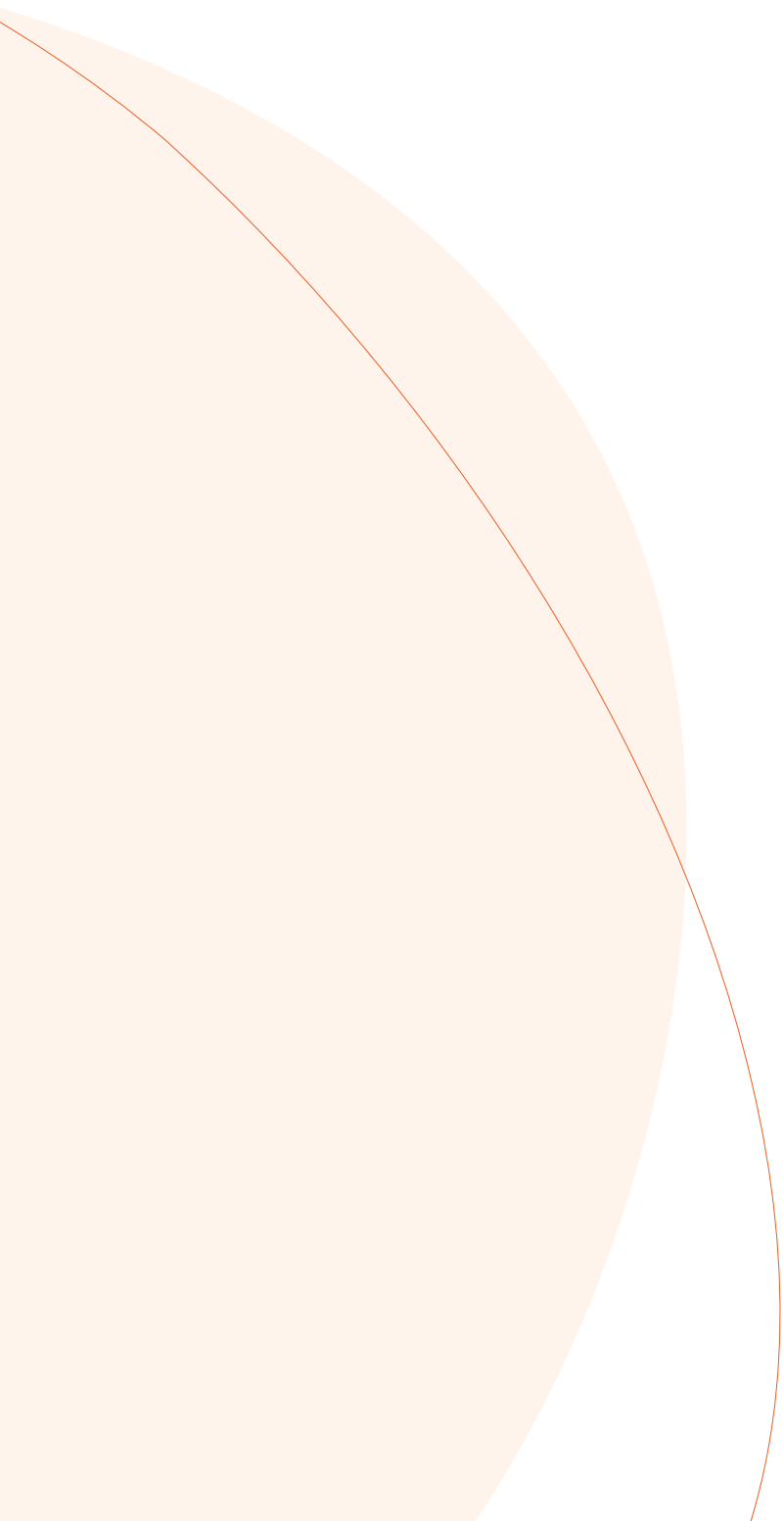

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