Living with Long Covid

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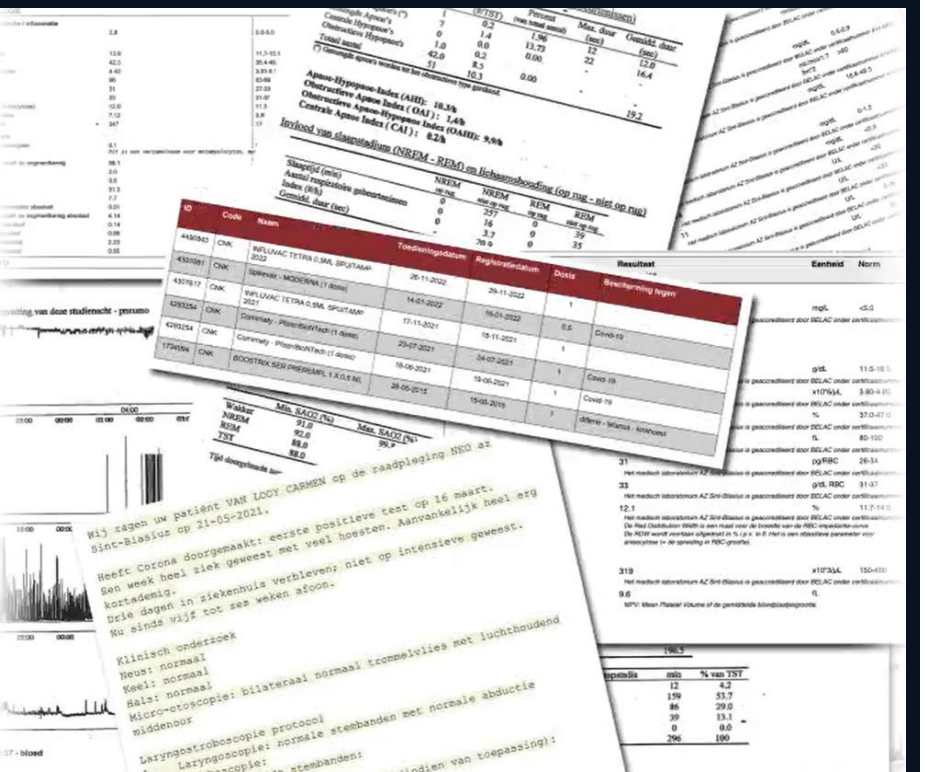
Mother of Ella (10)
Project Manager, Flemish Government
Long Covid Patient
Not Recovered Belgium
Patient Expert (PEC)



What living with Long Covid looks like

- 2021
  - March 18th: PCR positive and hospitalisation
  - After acute phase Long Covid kicked in
- June 2021
  - Rehabilitation in hospital
  - Vaccinations
  - Severe worsening of symptoms
- End of 2021
  - Bedridden
  - Use of a reclining wheelchair
- 2023
  - Government Care Pathway Long Covid
  - Worsening of symptoms
- 2024
  - ME/CFS diagnosis
  - CGT
  - Worsening of symptoms
- Mid 2025
  - Start of off-label **medication**
  - **Specialists familiar to PAIS**
- November 2025 - …
  - Able to walk and ride my bike
  - Functional for several hours per day
  - Pacing and adjusting medication necessary
  - Vulnerable for reinfections

Long Covid
for 1.833 days



- 78 fluctuating symptoms (out of 200 known symptoms)
  - Fatigue, PEM and energy production
  - Cognitive and neurological issues: brain fog, hoarseness, convulsions
  - Sleep disorders
  - Cardiovascular problems: orthostatic hypotension, body temperature regulation
  - Pain and global inflammation
  - MCAS
  - Hormonal issues
- 75 doctor's appointments in 12 hospitals, 18 specialists
- 115 tests (blood work, lung and heart tests, urine, cortisol,…)
- 35 scans and echos
- Dozens of therapy sessions
- Participated in 4 studies



Connecting the dots as a patient

- Repeating the same long story plus blood works to every doctor, therapist, in studies
- Not the right tests – nothing wrong?
- Doctors focus on 1 or 2 symptoms, even though it is a multisystem disease
- Data spread across systems, not accessible or easy to read for others
- No or incomplete reports by overworked specialists
- No single, complete overview to guide possible recovery

Long Covid in Europe and Belgium

- 36 million Europeans (1 in 30) - 550.000 in Belgium
- Multisystem disease with enormous impact on quality of life
- Overlap with other conditions (PAIS)
- Underdiagnosed and misdiagnosed, over psychologised
  - 80% female
  - Lack of investment in other post infectious diseases like MECFS, chronic Lyme,… (PAIS)
- Many ongoing studies worldwide
- Belgium:
  - No biomedical investments
  - No database: numbers of patients nor follow up
  - No policy for working with Patient Experts for studies or in rollout Care Pathways
  - Difficult to find studies and for studies to find patients

Ideal scenario

One accessible health record aligned over all professionals
Use of data to detect possible Long Covid for earlier and correct diagnosis
Inclusion of patient reported outcomes, daily functioning and quality of life
Patients receive insights from their data (compared to or enriched with global data)
Automatic invitations to relevant studies
Let patients be partners in knowledge creation about their disease