

Jonas – (no) life with ME/CFS

Written by Christian B., Jonas father

Status as of: February 27, 2023

Translation into English with the help of DeepL and my profound half knowledge in English, original text in German



Jonas in his care bed at the end of 2022

Inhalt

1. Why this document?	1
2. Short version for „#Millions Missing“	2
3. Jonas life until 2013 - before ME/CFS	3
4. Course of disease	3
5. Condition and symptoms of disease today	5
6. High burden on the family due to Jonas' illness and care	6
6.1 Care effort	6
6.2 Dealing with civil services - the bureaucracy monster	8
6.3 Financial situation and social protection	10
7. Therapies and medical care - tabular list	10
8. Environment - who reacted how to Jonas ME/CFS	11
8.1 Freiburg University Hospital 2014 - a catastrophic mistreatment	11
8.1.1 Jonas request to place a PEG tube	12
8.1.2 Psychiatrist interviews seriously ill patient - interview transcript November 5, 2014	13
8.1.3 Interview protocol with senior physician and physician on November 13, 2014	14
8.2 General practitioner until 2014 Dr. Prestel and nursing service Neff	15
8.3 Family, friends and acquaintances	15
8.4 Support group, ME/CFS organizations, other patients	16
8.5 Employers	16
9. Why doctors hold on to wrong beliefs for so long	17
10. ME/CFS sufferers could recover quickly if...	17
11. Worry about the future ? What could happen	17

1. Why this document?

After more than eight years of suffering, our son urgently needs a therapy that will improve his condition. More understanding of ME/CFS is needed among healthcare leaders, especially in hospitals, to avoid catastrophic treatment failures like Jonas' in 2014. I would like to use the account of our case to help raise awareness of the urgency of researching and treating ME/CFS so that my son can soon return to a dignified existence and our family can once again have a livable outlook.

This document gives comprehensive, structured information, e.g. for media representatives or other caring relatives and can be passed on. Please do not hesitate to contact me if you have any questions.

Christian B., jojusamba@gmail.com

2. Short version for „#Millions Missing“

See <https://www.millionsmissing.de/>



Jonas until 2014

Mountain hiking, games, music, theater, running,
friends, computer science
Very good high school graduation
Many plans: travel, study biology or geography
A great son, friend and person



Jonas in bed for 9 years - always

Extreme weakness, sensitivity to noise and light
Feeding via PEG tube
Pain, inflammation of esophagus
Not able to talk, no variety, "locked-in"
Hospitals, dramas without end
Care only possible at home
Heavy burden on the family

I don't know how much longer we will (have to) keep this up. Jonas' mother also suffers from ME/CFS.
The desperate father.

3. Jonas life until 2013 - before ME/CFS

Birthday: 18.10.1996

Jonas grew up in our house in Falkensee near Berlin, surrounded by lots of nature. Until his ME/CFS disease, Jonas was a healthy, happy and versatile boy with many hobbies and friends: On vacations, he always planned our mountain and island hikes with us and wanted to explore even more than his parents. He read many fantasy books and played theater since he was 12 years old. He could spend hours immersed in meticulous statistics, maps, etc., so he was also good at science. Only soccer he played as grotty as his father. Jonas is not an "overachiever," but he is very enthusiastic and ambitious. I infected him and his four-year-younger brother Julian with my passion for board games, and he was already playing games like Carcassonne, in which you plan and calculate strategically, before school started.

Only one event in his childhood may be related to his current illness: At the age of ten, Jonas had a one-off epileptic seizure followed by four months of severe exhaustion, for which no doctor could find an explanation.



2007 in Austria: Christian, Jonas, Andrea, Julian

Stressful for Jonas was our move to Freiburg in 2012, far away from all friends and relatives; he was 16 at the time. But he quickly made friends in the new environment. He was helpful and open-minded. Jonas was good with younger children, which came in handy for his younger brother's children's birthday parties. He has a very good relationship with Julian. In 2013, we were so taken with his positive development into an adult and our good relationship with him that I told friends about it. Not that he never had any problems. But they were few compared to many of his peers.

Without ME/CFS, Jonas would probably not be a Nobel Prize winner today, but he would certainly be a highly respected person and colleague with good social contacts. Our society loses a lot by not paying enough attention to ME/CFS. Not only money through missing social contributions and taxes, but great, dedicated people.

4. Course of disease

After a harmless infection in November 2013, shortly after his 17th birthday, Jonas' exhaustion and malaise persisted, initially especially after running training with his running group. Later, concentration difficulties, problems with the long school days, abdominal pain, difficulty swallowing and, as a result, weight loss were added to the mix. He had to give up all hobbies and concentrated only on the lessons relevant to his high school graduation. This was followed by a first hospital stay at the Children's University Hospital in Freiburg for clarification.

In May 2014 Jonas still made a very good high school graduation, but as it turned out afterwards with his last forces. From that point on, he was extremely weak and slept for many hours every day. Nevertheless, he couldn't recover during the summer. However, he still participated in family life and managed to gain 4 kilograms (10 pounds) again by eating constantly and slowly, despite his swallowing difficulties. On vacation in September 2014, he was still able to walk and bathe very slowly (at the pace of a 90-year-old).

Then strenuous visits to the doctor led to a sudden further deterioration. He got severe migraine-like headaches, balance problems and was suddenly sensitive to light. We thought of a brain tumor and unfortunately took him to the pediatric clinic again. This decision turned into a disaster. After five days of

program without any consideration of his weakness, he could no longer walk, could hardly move his arms, became more and more sensitive to light and noise, and had less and less strength to eat and speak. The further stay in the adult clinic became pure torture for Jonas. His numerous severe ME/CFS symptoms were misinterpreted by the clinic as psychological problems. They placed him in a noisy four-bed room despite the possibility of a single room. The nursing director refused to give him anything to drink or eat in his hands, despite his extreme weakness and urgent request for it, in order to force him to be active. When I came to his room in the afternoon of that day, he was lying in total despair with his back up in front of the tea standing twenty centimeters in front of him, too weak to take it himself. Thirsty, he immediately drank 400 ml, which I handed to his mouth. This treatment and the constant activation attempts led to a weight loss to 41 kilograms (= 90 pounds, height 180 cm or 5,9 feet, BMI 12.6, decrease 8 kilograms = 18 pounds) and complete immobility. Without his knowledge he was treated with psychotropic drugs. Jonas constantly begged us to take him home. The university hospital, however, wanted to place him in a psychosomatic clinic far away from Freiburg - under separation from his family. Even after a conversation between the ME/CFS-expert Mrs. Prof. Scheibenbogen from Charité Hospital in Berlin and the senior physician, it was still a long struggle until Jonas received a PEG tube. When he finally came home after almost five weeks of hospitalization, it was too late.

Since then, Jonas has never been able to leave his nursing bed. He is fed via the PEG tube. For half a year he continued to be completely immobile (he could only move one little finger) and became weaker and weaker. From the university hospital he brought home five pressure sores and the antibiotic-resistant *Pseudomonas* germ, which eventually affected his entire back. His pain - all over his body, severe headaches, pain with every touch - became so bad that he often wished for an induced coma because he couldn't take it anymore. Twice we observed mild epileptic seizures while he slept. On the advice of the English ME/CFS expert Dr. Nigel Speight, we started giving immunoglobulins in March 2015 and, as he also suspected Jonas to have Lyme disease, low doses of doxycycline. Jonas' condition then stabilized. He regained weight and began to move his arms in his sleep. However, starting in May 2015, he was plagued by constant wandering severe pain in his muscles and joints. At times, we could barely accommodate his requests for cooling to relieve pain, and we were finally at the end of our rope despite hiring a nurse. In May 2015, a strong *Yersinia* strain was also detected. Since the beginning of 2015, Dr. Andreas Schwald was our primary care physician. He performed standard examinations on Jonas and visited us regularly at home. His help was the basis for Jonas' treatment at home being possible at all.

The antibiotic therapy started in June 2015 by the Lyme disease expert Dr. Weitkus then brought an incredible turnaround: After a few days of clarithromycin, the pain almost completely disappeared. In the following months, we were all optimistic that Jonas would soon gain his healthiness entirely. Jonas became mobile again, listened to music, radio plays, news and we talked and laughed a lot. Permanently he received alternating antibiotics and numerous other remedies. A physical therapist visited him weekly. But since November 2015, Jonas' headaches and weakness increased again. From February 2016, another Lyme disease expert, Dr. Hopf-Seidel, advised us. Three months of further antibiotic treatment followed. At first with success, because he was now eating one meal a day again for two months. But in April 2016 these improvements ended, his weakness increased a lot and communication with him was very difficult again since he could hardly speak and was extremely sensitive to noise. Increasing digestive problems led to the fact that we had to further reduce the amount of food.



Oct. 2015: In a good mood thanks to antibiotics

From the summer of 2016, we carried out a mitochondrial therapy according to Dr. Kuklinski, extensive laboratory analyses followed and we were advised by the Viennese alternative practitioner Rudolf Fischer, who was recommended by Dr. Kuklinski. On his advice, we changed Jonas' diet to a higher-fat

tube feed and Jonas gained weight again as a result. However, the recommended dietary supplements did not bring any improvement. Alternative treatments by the Freiburg alternative practitioner Sabine Schliebusch were also unsuccessful.

Starting in February 2017, Jonas began to experience severe heart palpitations, which led to anxiety, massive digestive problems, and severe headaches again. Due to his weakness, he could hardly move and could no longer listen to the radio. These new problems led to another hospital stay: In Lahr, Jonas was examined very intensively in the neurology department, also for rare diseases. Result: no findings. In 2017 there were no laboratory markers for ME/CFS. In contrast to the Freiburg University Hospital in 2014, he was treated well in Lahr and consideration was given to his great sensitivity to sensory stimuli. The senior physician praised Jonas' willingness to cooperate during the numerous examinations. The further treatment we had planned in the Schmieder Clinic in Heidelberg did not take place, as the medical director there strongly advised us against it due to his experience with ME/CFS patients.

Jonas' problems with digestion and rising stomach acid continued to increase. He could no longer tolerate the industrially produced tube feeds and since then we have to prepare the food ourselves every day, puree it and give it manually with a syringe. We calculate quantities, nutritional values, etc. precisely and the recipes change regularly. In 2020, Dr. Wimmenauer diagnosed eosinophilic esophagitis, which causes difficulty swallowing and weight loss and had probably been present for many years. This is a chronic esophagitis triggered by allergic reactions to certain foods. Since 2021, we are advised by Dr. Schlenker, an environmental physician, who ordered many blood and urine tests. Based on the lab results and his suggestion, we avoid the foods that are allergenic to Jonas and give various supplements such as vitamin E or selenium. His digestive and esophageal problems slowly decreased.

In January 2021, Jonas survived a dangerous bout of pneumonia that was cured with only the second antibiotic. His corona infection in the fall of 2022 was relatively harmless. In the summer of 2022, our family doctor Dr. Schwald died, which deeply shook us. However, we are very fortunate that his son-in-law as well as his daughter, both physicians themselves, who took over his practice, continue to provide us with primary care and also make house calls.

Further therapy attempts were made based on positive experiences of other severely ill ME/CFS-patients and the general recommendations of Mrs. Prof. Dr. Scheibenbogen from Charité Hospital in Berlin: Antiviral therapy with Viread from November 2017 until May 2020 ultimately brought no improvement. Since April 2021 we treat Jonas with low-dose Abilify, since November 2021 additionally low-dose Naltrexone. Whether the slight improvement of Jonas' condition since 2022 (see next item) is related to these two drugs is unclear.

5. Condition and symptoms of disease today

Jonas' condition and symptoms fluctuated significantly since 2014. Throughout was the great sensitivity to sensory stimuli, especially noise and light. He was never able to leave his bed. Any trouble or commotion usually worsened his condition ("crash"). Since spring 2022, his condition has improved and stabilized somewhat. He endured the relocation in summer 2022 from Freiburg to D. without any problems and the quiet environment in his new home is recreative for him. Symptoms today are:

- Extreme weakness, continuous bedriddenness, transportable only under sedation. Since spring 2022 slight improvement. He can move his legs and arms again, but he cannot turn onto his side.
- Light sensitivity: eyes darkened with a washcloth since Nov 2014, but since spring 2022 he often does not need the cloth for a longer time after waking up and he even opens his eyes. However, he cannot maintain eye contact.
- Noise sensitivity: constantly wearing a silicone hearing protector. Since spring 2022, slight improvement so that he can be addressed at almost normal volume.
- Swallowing problems - food and liquid only via stomach tube
- Body care extremely stressful for Jonas

- Fully conscious, mentally fully aware. From August 2015 to May 2017 listening to the radio for a few hours a day, since June 2017 no longer (mostly word contributions Deutschlandfunk and music via Ipad). Since spring 2022, Jonas is sometimes relaxed enough to smile again. He is now able to listen to his brother who is telling him in bits and pieces about life outside once a day.
- Willpower: Jonas is determined to get well again and participate in life. He wants us to actively seek therapy and, if necessary, go public about it.
- Communication since 2018 only by tapping his hands. Knocking means "yes" to a question from us. However, he often doesn't knock the first time and it takes us a long time to figure out what he wants.
- Sensitivity to touch and movement: He needs a long time to adjust before any care actions.
- Pain? For years, Jonas had extreme headaches and other pains all over his body. For seven years he permanently had an ice-cold cooling pad on his head, which had to be renewed every 30 minutes. Since two years this is not necessary anymore and he does not receive any painkillers. He probably endures pain during movements.
- His sleep rhythm was completely out of whack until the beginning of 2022. Since then, predominantly night sleep again.

6. High burden on the family due to Jonas' illness and care

There are no treatment centers for patients like Jonas in Germany, so we have to care for him at home. The constant burden on our family is almost unbearable. Our younger son Julian was very affected by Jonas' illness. He was 14 years old at the time. Now he is starting therapy to cope better with it. At the moment, Julian has interrupted his studies to support the care of his brother and to be there for him. My wife Andrea cannot treat her own ME/CFS disease and is doing very poorly. I lost my job as a senior manager in 2016 because of Jonas' extensive care, was unemployed for 1 ½ years after that, and can now work almost only in my home office. I never had a vacation for 9 years, never a free weekend and never could go to my sick parents in Berlin anymore. For 7 years Jonas rarely slept at night and even then I had to spend hours with him. We could hardly receive visitors. Most of the therapies we tried with Jonas so far we had to organize and finance ourselves, because the few experts for ME/CFS in Germany are completely overloaded. In the following detailed information.

Andrea, mother: Born 1965, nutritionist, suffering from ME/CFS for about 20 years. She always felt better in warmer climates and a pollution in our house in Falkensee near Berlin affected her health. These were the reasons for our relocation to Freiburg in 2012.

Christian, father: Born 1964, Dipl. Kfm., since 1992 various management positions, works for the city of Emmendingen today.

Julian, brother: Born 2000, geology studies currently interrupted due to Jonas care.

6.1 Care effort

Jonas' care involves about 16 hours a day.

External caregivers: Since 2017, we have been supported by Polish nursing assistants who live with us permanently (approx. € 34,000 costs per year). For about three years we have the great fortune that Wioleta is with us and there has been no change of caregivers since then. Because of Jonas' great sensitivity to all sensory stimuli, it takes two weeks to train a new caregiver. It is not possible to speak loudly with Jonas and he himself cannot express his wishes. It takes a lot of tact and experience in dealing with him. Often it did not work out with a new caregiver and then we were again on the search. Our care agency Pflegehelden Freiburg was always very helpful. We had to have our apartment remodeled in 2017 to create another room for the nursing assistants. However, without the nursing

assistants, I would not have been able to go back to work in 2017! We take great care not to overload the nursing assistants (= compliance with labor law) and to be considerate of their needs.

At the end of 2014, when Jonas became a nursing case, we had hired nursing services whose costs were covered by the nursing care insurance. However, care services with fixed and short visiting hours, changing caregivers and very limited services are unsuitable for Jonas' care. However, we learned a lot from these care services during this time, for example, the treatment of Jonas' PEG wound. When I became ill in the spring of 2015 and Jonas' condition became increasingly difficult, we hired a professional nurse for eight months. At that time, I was his employer with all the associated duties, especially paying off social insurance, etc. However, this solution was not financially viable for us in the long term with costs of over € 5,000 per month. It was also difficult to find a suitable nurse.

Nutrition: Since Jonas can no longer tolerate the industrial tube feed, the food has to be prepared anew every day (duration incl. pureeing etc. over 2 hours), with changing recipes, with nutritional values calculated in Excel. The self-prepared food is not thin enough to run over the pump. Every day 6 meals are given with a syringe via the tube on the PEG tube (duration 45 minutes each incl. working around it).

Personal hygiene: Jonas has to be taken care 24/7. Even at night, I often have to look after him when he calls out on the alarm clock on his wrist. Because of his extreme sensitivity, all care activities require numerous attempts. Jonas can never leave his bed and can hardly move himself.

Giving medicines and dietary supplements: Currently 5 medications and 12 supplements according to test results (blood, urine) and doctor's prescriptions. Entry into a list, observing times and compatibility (with each other, before / with or after food, time of day). Nursing assistants are not allowed to give medications; we have to do that.

Communication with Jonas is very laborious. He is using hand signals to yes/no questions. When he wants to know something or communicate something, it can take hours to figure out what it's about. Especially since he can't always respond the first time, so you have to ask the same questions several times.

Organization: purchases of fresh food (every 2 days), ordering medications, materials and supplements in coordination with physicians and health insurance (prescriptions, applications, about 20 different regular suppliers). Material is e.g.: PEG tubes and syringes, underlays, ointments, disinfectants, compresses and dressing material for the PEG wound. Prepare lists to record medication and nutritional supplements. Communication and correspondence: since 2017, approx. 3,000 emails and numerous phone calls, letters, etc. 2022 e.g. with health insurance, care insurance, care agency, care advisor, doctors, child benefit office, local court, social welfare office, job center, tax office, self-help institutions. Initiatives for new treatments.

Additional housework: increased hygiene effort: daily wet wiping, laundry washing, etc.

Special events:

Every year, there are special events that generate significant additional maintenance work. In 2022, for example, these were:

- The health-related move from Freiburg to D. Reasons were the inadequate emergency escape route for Jonas from the 2nd floor, shisha smoke of the neighbors and increasing noise. After moving most of the household goods, Jonas' move required the accompaniment of the family doctor because of his sedation, a technician from the company Storch & Beller to dismantle and set up the nursing bed, paramedics for Jonas' transport. Applications to the nursing care insurance company for improvements to the living environment. A lot of effort until the processes were working again. Examples: Any drilling of holes for dowels in the apartment must be coordinated with Jonas in advance and he must be fitted with noise protection earphones.
- The Corona infections of Andrea, Julian and finally Jonas (each in turn). Each time additional measures to prevent infection, which unfortunately had limited success. Considerable additional effort

in Jonas' care. Hopefully no long-term consequences.

- The multiple defect of the mattress of the care bed: Storch & Beller needed on weekends, Jonas transport from the bed organized, etc.
- The defect of Jonas earplugs, which he needs permanently as noise protection. Impression of the inner ear required, appointment of the service provider at our home, ear cleaning beforehand, etc.

6.2 Dealing with civil services - the bureaucracy monster

In the 2nd half-year 2022 I have made very positive experiences with civil services and authorities ! Altogether I surely had contact with ten or more coworkers of different offices (see below), which were mostly very concerned by our fate and applied their regulations in our sense. And partly they moved very fast. For example, as the employee from the Social Welfare Office told me that a Polish nursing assistant would be financed, he clarified that this had never been done before. Our financial situation has improved a lot, especially in the long term, and it gives us hope that the attitude towards ME/CFS has changed fundamentally in many civil services and authorities. This is certainly also due to the many media reports.

Otherwise, however, the time required is high, the numerous regulations are very complicated and you first have to find out about many regulations that you could use. And then the work really starts: finding out about regulations, submitting applications, communication, objections, proofs. E.G.:

Care insurance: determine the need for long-term care and care allowance: To determine the need for care, an application must be submitted to the care insurance. The medical service of the health insurance companies then determines in an expert opinion whether and which degree of care is available. As a rule, an on-site visit by the expert is required. In my 2023 application for an increase from care level 4 to 5, I submitted 13 additional documents in addition to the application. In the early days, we had hired nursing services, the costs of which were borne by the care insurance at the time. However, for Jonas' care, care services with fixed hours, changing caregivers and very limited services are unsuitable. We therefore receive a monthly care allowance for the care we provide ourselves. The health and care insurance provider BKK VBU also covers many other costs, e.g. for Jonas' very elaborate nursing bed with anti-decubitus system and a large part of the materials, e.g. for the care of the PEG wound or syringes for feeding. Medical prescriptions are required for these.

Health insurance: application for cost coverage in individual cases: We made several requests to the health insurance company to cover special costs, e.g. for Jonas' treatment with cannabis tea, which was rejected.

Care insurance: preventive care budget and transfer of short-term care budget: If a caregiver is prevented from providing care, e.g. due to their own illness, and a replacement is to be organized for this, the costs can be applied for from the care insurance fund. However, this is complicated, financially limited (2022 max. 2,418 € per year) and was rejected in some cases, in others approved. Approved was e.g. the assumption of a night watch of the evangelical social station, when Jonas was somewhat better for a while, but he was awake throughout the night and prevented me from sleeping, sometimes the whole night. Being able to sleep almost undisturbed at least two nights a week was then important for me and this request had paid off.

Care insurance: Nursing care support allowance can be claimed by anyone who suddenly has to help out acutely with the care of a relative, e.g. because the regular caregiver is absent. The long-term care insurance then takes over a large part of the salary payment for a few days if the employer certifies the time off due to the emergency. Occurred in 2022.

Employer: special leave due to care needs of relatives: In accordance with the Care Time Act (Pflegezeitgesetz), in part probably also regulated by collective agreement (?). Also in the case of sudden special care needs of relatives.

Health insurance: reimbursement of medication co-payments: The health insurance provider reimburses co-payments that exceed the 1% burden limit (for seriously ill patients) on an annual basis. The procedure is very complex. First, you have to record all items including the co-payment amounts and estimate whether a claim is worthwhile. Invoices and proof of payment must be submitted for each item, as well as the income tax assessment. If not everything is recognized by the health insurance provider, it can happen that you slip under the load limit and get nothing or much less than expected. If you have very little income, you can apply for a general exemption from co-payments. That is then certainly less laborious. Unfortunately, that was never an option for us.

Tax office (Finanzamt): claim tax refund due to extraordinary expenses: In the tax declaration, one must prove that the expenses were extraordinary, inevitably incurred, and necessary and reasonable. Statements and private prescriptions from doctors are important for this. I recorded every expense that was not directly reimbursed by the health or care insurance provider and kept or submitted the collected receipts for review. Every time you go to the pharmacy, order online, etc., you have to remember to research and prove payments over the account later if necessary. If partial reimbursements were made (in our case, for example, care allowance), this also had to be entered. Every year, this involved a total of 150 - 200 individual items. This kept me busy for several hours each year, but was very worthwhile: A large part of our income and church tax was reimbursed until 2021.

Care insurance: pension insurance for caregivers: The care insurance provider pays pension insurance contributions for Andrea (mother). She is a non-employed caregiver with no other job. For this purpose, the extent of her care activities had to be proven.

Care insurance: improvement of Jonas' living environment (safety): A large part of the relocation costs was covered by the care insurance due to the proven improvements for Jonas (applications with data, photos, written descriptions, etc.). The staff at the care insurance company BKK VBU were very helpful and sympathetic to our situation.

Care insurance/care consulting: According to § 37 Abs.3 SGB XI (social code) one must receive a certified care consulting quarterly to ensure the quality of care. Otherwise, the care allowance is cancelled. We owe a lot to our care consultant. She suggested the following points "Appointment as guardian" and "financial help for Jonas' care".

Local district court (Amtsgericht): appointment as guardian: We, his parents, have been able to represent Jonas since 2022. This has changed a lot for us. We no longer have to worry that someone else will be appointed as guardian and representative for Jonas and that then Jonas will be forcibly committed to a psychosomatic facility, as was attempted in 2015. We can now go public with Jonas' case. We have been able to provide signatures for Jonas since 2022 and thus could apply for "social assistance" for his living expenses, see next items. For the appointment as guardians, however, four home visits to us and Jonas were necessary with the following result: A specialist in psychiatry and psychotherapy prepared a specialist medical opinion, a social pedagogue a social report, a procedural guardian suggested us as guardians and finally the district judge personally stopped by. No one doubted ME/CFS as the cause of Jonas' condition and all expert opinions and reports agree with the facts from our point of view.

Office for social affairs (Amt für Soziales): financial help for Jonas' care: We had applied for "social welfare", because Jonas was already 25 years old and has no income. At the end of 2022, it was decided that the entire costs for our Polish nursing assistance (almost 34,000 € per year) would be covered, minus the care allowance (10,800 € per year) that we already receive from our care insurance provider. As described above, our financial situation has improved significantly. The office for social affairs has determined that no other solution is possible for the care of Jonas and in his very special case no normal care service comes into question. The employee said that this decision was a novelty. - I conclude: If we had applied for this a few years ago, it probably would not have been decided this way.

Jobcenter (Freiburg and Emmendingen), benefits to secure livelihood: The office for social affairs Freiburg forwarded my application for social welfare for Jonas from May 2022. Due to our relocation from Freiburg to D. in August 2022, the Jobcenter Freiburg was responsible for the time before, and the Jobcenter Emmendingen for the time after. The two applications, which had to be submitted again in the correct form, were incredibly time-consuming; 24 pdf attachments went to the Jobcenter Freiburg, for example. One must prove the living conditions quite exactly, in particular financially. But the employees there were just as unbelievably accommodating and helpful, even apologizing for the complicated procedure and pulling out all the stops, so that after just a few weeks we received positive notices and about 700 € per month as a contribution to Jonas' living expenses, even retroactively since May 2022.

Federal Employment Agency, child benefits: We continue to receive child benefits for Jonas due to his disability, although he is already over 25 years old. This must be proven annually by medical certificates.

6.3 Financial situation and social protection

Overall, we are now well secured: Through existing reserves due to the sale of our semi-detached house in Brandenburg in 2013, through our social network - our families/ relatives are very important - and especially due to the positive decisions of the civil services in Freiburg and Emmendingen 2022/ 2023. My employment with the city of Emmendingen is also essential, not only because of the current income, but for the payment of social security contributions. I have always observed tax regulations and we have never employed anyone illegal.

"Normal" living expenses: Due to the care situation, a large apartment with five bedrooms is required, but we have no expenses for vacations or free time, since we have to be present virtually around the clock.

Costs for medication and care not covered by health or care insurance have averaged around € 40,000 per year in recent years.

Regular income: Only Christian B. earns a regular income, as an employee at the Emmendingen municipal administration. However, this income would not be nearly enough to cover our living expenses.

Asset withdrawal and family support: In 2013, we sold our semi-detached house in Falkensee near Berlin. Thus and on the basis of the support of our families we were able to bear the high additional costs, especially in the years 2015 to 2021.

Tax refund: I claimed our illness-related costs as extraordinary burdens until 2021, as a result of which a large part of the income and church tax was refunded.

Monthly care allowance from the care insurance, care level 5 since December 2022

Reimbursement of the costs for our Polish nursing assistance since the end of 2022, less care allowance from the care insurance, see above under "Dealing with civil services".

Benefits to secure livelihood, see above under "Dealing with civil services"

Child benefits, even beyond Jonas' 25th birthday, see above under "Dealing with civil services"

7. Therapies and medical care - tabular list

Family doctor:	Mr. Dr. Schwald 2015 – 2022, Mr. Dr. Weber since 2021 (Mrs. Dr. Prestel until Nov. 2014, Mrs. Dr. Ullmann at the end of 2014)
Environmental physician:	Mr. Dr. Schlenker since 2021

In the chapter "Course of the disease" the most important therapies and incidents are already mentioned. Here again briefly and with naming of the main physicians who were our advisors. Since 2014 Jonas received probably more than 100 further remedies, mainly oral nutritional supplements (ONS) such as vitamins and in addition medications for acute complaints, which are not listed here. Also not listed are treatments for individual symptoms. Most of the therapies were only possible because they were coordinated with Dr. Schwald/Dr. Weber and the drugs were prescribed by them and, in the case of intravenous drugs, also administered. They also took numerous blood samples and arranged for laboratory tests.

Period	Therapy	Medication	Physician	Impact
10/2014 - 01/2015	Cortisone	Cortisone	Dr. Ullmann	None
02/2015 - 10/2015	Immunglobulins	14 *200 ml Intratect = 12,325 € Cost	Dr. Speight (England)	Vital forces came back
06/2015 - 06/2016	Lyme disease treatment	12 antibiotics, see below* and additional remedies (ONS)	Dr. Weitkus, Dr. Hopf-Seidel	Phenomenal at first, then unfortunately declining
09/2016 - 03/2017	Mitochondria-th. according to Dr. Kuklinski	25 (!) ONS	Alternative practitioner Rudolf Fischer, Vienna	ONS none, but nutritional change was important
01/2017 - 06/2017	Lyme disease and viral treatment	tinder fungus, tincture etc.	Alternative practitioner Sabine Schliebusch	None
03/2017 - 06/2017	Bemer therapy	Bionic 880	Alternative practitioner Sabine Schliebusch	None
11/2017 - 05/2020	Antiviral therapy	Viread, (Isentress), ONS	Mrs. Voss (no doctor, book author)	After all none
04/2021 – lfd.	Low-dose-Abilify	Abilify	Prof. Scheibenbogen	Slight improvement ?
09/2021 – lfd.	Micronutrient therapy	8 ONS	Dr. Schlenker	Slight improvement ?
11/2021 – lfd.	Low-dose-Naltrexon	Naltrexone	Prof. Scheibenbogen	Slight improvement ?

* Antibiotics administered (Lyme disease treatment): *Clarithromycin, Cefixim, Ceftriaxon, Minocyclin, Azithromycin, Roxithromycin, Fluconazol, Metronidazol, Tetracyclin, Ultreon, Doxycylin, Eremfat*

Therapies that we cannot try are those that would require Jonas to leave the house or require daily infusions and thus doctor/nurse attendance. In addition, oral medications are currently not possible; everything must be administered via the PEG tube.

8. Environment - who reacted how to Jonas ME/CFS

8.1 Freiburg University Hospital 2014 - a catastrophic mistreatment

He was still able to walk in. One month later he came out life-threateningly emaciated, 100% bedridden, unable to move, tormented by pain. He barely survived. **The wrong treatment in the University Hospital of Freiburg made Jonas a seriously ill patient.**

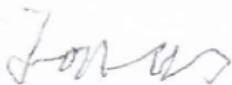
The course of treatment at the University Hospital in Freiburg has already been described under "Course of the disease". As concrete and detailed examples, I enclose below protocols that I made at that time immediately after the talks and meetings.

Note: I am not imputing bad intentions to anyone. The attending physicians and nurses certainly wanted only the best for Jonas and acted according to their training and convictions. I myself had an excellent experience at the University Hospital Freiburg in early 2014 and was very grateful for the treatment of my atrial fibrillation (surgery ablation). Paradoxically, I was in the ward opposite the one Jonas was then in a ¾ year later, where he and we had such nightmarish experiences. Why I think doctors hold on to wrong convictions for such a long time, I have described in an extra chapter further on.

8.1.1 Jonas request to place a PEG tube

Erklärung

Ich, Jonas [redacted] bitte um Legung einer PEG-Sonde, denn ich habe Angst zu verhungern. Die Nasen-Sonde habe ich nicht vertragen. Ich möchte dringend wieder zunehmen, bin aber zurzeit noch nicht in der Lage, genügend Nahrung zu schlucken: Es erschöpft mich zu sehr und verursacht mir Kopfschmerzen.



Freiburg, den 15.11.2014

Only after a long back and forth the university hospital was willing to place a PEG tube

Translation of the writing above: „I, Jonas ... ask for a PEG tube to be placed, because I am afraid of starving to death. I did not tolerate the nasal tube. I urgently want to gain weight again, but at the moment I am not yet able to swallow enough food: It exhausts me too much and causes me headaches. Jonas...

Freiburg, 15.11.2014“

8.1.2 Psychiatrist interviews seriously ill patient - interview transcript November 5, 2014

Participants: Prof. van Calker/ Uniklinik Freiburg (psychiatrist), Jonas (patient), Christian (father)
The protocol was written by Christian directly after the interview.

Psychiatrist interviews seriously ill patient who can barely speak

University hospital of a large city on November 5, 2014, 12:30 p.m. - Imagine:

Patient, 18 years old: An emergency: Extreme exhaustion, severe pain, especially in his head, but also in all limbs, unable to move, almost as if paralyzed, extremely sensitive to noise and light - eyes darkened with cloths, icy cooling pad on the head, noise protection headphones put on like the jackhammerers use them, every spoken word means torture for him. For months he had been examined for all kinds of things, by dozens of doctors, each of whom had been questioned again and again from the beginning, he had been tormented with drugs, many hopes had been raised and disappointed. When he was still better, a psychiatrist of the same clinic, where he is now, had certified him, that there were no indications of depressiveness and suicidality - he was friendly and cooperative; so it was written in the doctor's letter. And now he has landed in this extreme state, completely helpless and he only wants to rest and that this unbearable pain finally stops.

Father sits next to the patient.

Psychiatrist enters the room: "Hello Mr. B., I am a psychiatrist. May I ask you some questions?"

Patient: pause pause pause - "No." He stammers out the words with the last of his strength, barely audible.

Psychiatrist: "Why don't you want to talk to me?"

Father then asks in amazement if the psychiatrist doesn't know about his terrible condition, that he is extremely exhausted and in great pain?

Psychiatrist: "Who are you?"

Father: "His father." One introduces oneself.

Psychiatrist again to the patient: "But we only want to help you. Don't you want to be helped?"

Patient: Pause, to his father: - "Dad, I can't do this anymore." Pause - "He should go."

Father: "It is better to tell him again yourself how you feel."

Patient: "Bad."

Psychiatrist: "And so you are in pain?"

Patient: "Yes."

Psychiatrist: "Where do you have pain?"

Patient: "Everywhere."

Psychiatrist: "What do you mean everywhere? How does the pain manifest itself and where? For a long time?"

Father to the psychiatrist: "But it's written in all the doctor's letters, in all the documents, why didn't you read that? Don't you realize that every word hurts him? He simply can't take it anymore, he's completely exhausted. He doesn't have mental problems, he needs something for pain, not an interview."

Psychiatrist: "You can't judge that." To patient: "Have you had suicidal thoughts?"

Patient: Pause. "No. I need rest."

Psychiatrist: "But you want to get better, don't you? What would have to happen for you to get better?"

Father: "That can't be, what's the point of these questions, it's not doing him any good!"

Psychiatrist: "Would you please leave us alone."

Patient pleading to his father: "No, he should go."

Father to son: "After all, it's better that way, he has to hear it from you, they don't believe me."

Father complies with the request and leaves the room.

After five or ten minutes, the alarm button rings from the room and the light outside flashes - every patient has such a button with which he can call a nurse. The father sees it and goes back into the room.

Father: "Jonas, what's up, do you want to be alone now?"

Patient: "Yes, he should finally go."

Father to psychiatrist: "I think it's better if we talk now, just the two of us, and I'll explain all the circumstances to you. My son is no longer able, as you can see."

The father then spends half an hour explaining to the psychiatrist what has happened in the last year, using his chronologically prepared documents.

Such questioning in extreme exhaustion is like forcing a patient to participate in group talk therapy after three days of atrial fibrillation at 200 pulses per minute and wondering why he is not saying much.

8.1.3 Interview protocol with senior physician and ward physician on November 13, 2014

Just as one example of several protocols in November 2014.

Meeting with senior physician Mr. PD Dr. Christoph Neumann-Haefelin and Mrs. Dr. Schmidt,
11/13/2014, 2:30 p.m., 11/13 evening wrap-up.

Clinic for Internal Medicine II, Gastroenterology, Hepatology, Endocrinology and Infectiology

- The university hospital wants to force Jonas into a psychosomatic clinic in Göppingen. They refuse to place a probe. So we would have no choice, because then we would not be able to care for him at home.
- On Tuesday, Jonas was still being pressured to have a gastroscopy; home care for Jonas was being prepared. Then, on Thursday, it was suddenly said that this was much too dangerous in Jonas' condition. What has changed in Jonas' condition during this period? Actually nothing, except that the tube through the nose caused him increasing pain and problems with mucus, colds, stronger sore throats - which spoke for the tube through the stomach and not against it. Wednesday was the visit of the chief physician. What did he say? - Is it a coincidence that the opinion of the doctors Neumann/Schmidt "changed"? I don't think so.
- Nursing service: I have to call Ms. Krämer to see if everything is being prepared further for Jonas' coming home or if it has even been stopped.
- What the doctors did not see (but the nurses did) was that the nasal tube had to be removed urgently.
- If I hadn't asked four times whether the new tube with an abdominal outlet would be inserted tomorrow, they would have easily let it slide.
- Dr. Schmidt said that all of Jonas' criteria also apply to depressive patients. This is not true. Strong exhaustion, often delayed the next day, after movement, after any physical and mental exertion, is not typical for depression. Dr. van Calker's performance at Jonas was incredible - like a bad movie, I could hardly believe it. I made a transcript of the conversation and have it ready.
- Single room would have been possible! Some nurses just shake their heads; they have recognized that Jonas needs rest. One nurse had even prepared a vacant single room! But the doctors don't want that. Probably because van Calker and others said that the "depressive" boy should not isolate himself and is therefore deliberately left in the four-bed room. Jonas' extreme sensitivity to light and noise and the pure pain and exhaustion both cause him is the typical feature for severe ME/CFS cases, but is interpreted by the doctors as a psychological problem ("shutting off"). This will certainly be the same in Göppingen and will harm him further.
- No matter what you say, it is interpreted as a psychological problem. Jonas was independent => the child was overloaded. Jonas had a good relationship with his parents => not age-appropriate parent dependency.
- ME/CFS understood? Shortly before the goodbye, Dr. Neumann-Haefelin said that this was also a mental illness. This is wrong. ICD10 classified under G93.3 = severe organic disease, coding to mental disease is not allowed.
- What we are going through here right now - being put into the psycho box because you don't prove anything else and they don't want to understand ME/CFS, is what all ME/CFS sufferers in Germany are going through. Everybody reports about the double struggle, many let themselves be written mentally ill, although they are not, so that they are e.g. written occupationally incapacitated, in order to somehow survive financially.

8.2 General practitioner until 2014 Dr. Prestel and nursing service Neff

Again, no one involved had bad intentions.

In November 2014, the nursing service of Mr. and Mrs. Neff was referred to us by the university hospital. Only one week after Jonas' discharge from the hospital, the nursing service attributed Jonas' difficult condition to our allegedly inadequate care, although we had reported the difficulties of his stay at the hospital. Without our knowledge, Mrs. Neff turned to our family doctor at the time, Mrs. Dr. Prestel, and claimed that Jonas was not receiving enough nutrition from us and that we were not able to care for him and that he was therefore in acute danger. Dr. Prestel, who had already tried to have Jonas admitted to a psychosomatic clinic in cooperation with the University Clinic of Freiburg, then reported us to the district court with an urgent application. All without any consultation with us. It then turned out that Mrs. Neff had not seen that our tube feed was highly caloric and corresponded exactly to the prescribed amount. Nevertheless, there was no apology. The Neff nursing service continued to insinuate that we were acting irresponsibly because we were not following the recommendation of our family doctor and terminated its contract with us. Even information material and a shown documentary film about ME/CFS did not change the opinion of the nursing service. And Dr. Prestel thought that someone with such a low weight should be treated in a clinic. The fact that it was the university hospital that had brought him to this lamentable state in the first place was not an argument for the doctor.

What does this show? Both our family doctor, Dr. Prestel, and the Neff nursing service initially made a very understanding impression when we reported that we assumed that Jonas had ME/CFS. But we were deceived. Behind our backs, they tried to force us into being admitted to the psychosomatic clinic. Urgently needed painkillers for Jonas, which he had received at the university clinic, were not prescribed.

Dr. Schwald, who had already been my general practitioner by then, immediately took over Jonas' care as well. Together with the physician Mrs. Dr. Ullmann, who also supported us at that time, he answered all the questions of the district court and those of the medical service of the health insurance companies during their visit at our home. Without their care and their statements that Jonas would be optimally cared for and nursed at home, Jonas would probably have been forcibly committed to a psychosomatic clinic.

8.3 Family, friends and acquaintances

When my wife Andrea received her diagnosis of ME/CFS from the Charité in Berlin (Prof. Scheibenbogen) many years ago, some relatives were still very skeptical whether there might yet be some psychological cause after all. Andrea's disease is not visible and many ME/CFS patients have this problem. With Jonas it was completely different. His health crash was so severe and my reports about our efforts in the months before were so extensive that our family members, even distant relatives, took and take a great interest in the fate of our family and support us as far as they can. For example, Andrea's sister even took a vacation during the worst time and supported Jonas' care with us. Petitions like the one for the hearing in the German Bundestag are supported and much more. For us it is also important that in case of an emergency this social network could help.

Friends and acquaintances could never visit us in the last 8 years because of Jonas' extreme sensitivity to noise. We would also hardly have had time and Andrea was usually much too unwell for that. I can hardly make long phone calls because I am often interrupted. My longer absences and appointments are reserved for my job. Therefore, most contacts are only by email.

The great sympathy for our fate from family, friends and acquaintances is very important to us and we report this to Jonas. Two of my former colleagues from Gegenbauer have undertaken many touching activities over the years, in addition to letters and emails, e.g. flower arrangements via Fleurop or a suitable book.

8.4 Support group, ME/CFS organizations, other patients

Without the support of the ME/CFS Freiburg self-help group, the Lost Voices Foundation, Fatigatio and patients with years of experience (Katharina Voss, author of the book "ME") we would hardly have been able to provide Jonas care. We are very grateful for all the advice and support we have received. The exchange of experiences is essential and together with other affected people one can achieve much more than as a lone fighter.

8.5 Employers

Jonas still graduated from high school in 2014, but he never had any experience with employers. I (Christian B.) am the sole breadwinner for my family. ME/CFS had a significant impact on my professional career: Because of my wife Andrea's illness, we moved from Falkensee near Berlin to Freiburg, and I had to give up my long-standing employment with the Gegenbauer Group as a result.

I had been working at Freiburger Stadtbau GmbH since 2013. When I tried to describe our difficult situation and Jonas' illness to my boss there in 2015, he immediately blocked it; he wasn't interested. He refused home office and literally said to me, "I need you here as a controller, not as a faithfully caring family man." Zero empathy, unlike many understanding work colleagues. Because Jonas' care and this job could no longer be reconciled, I was eventually unemployed for about 1 ½ years. Today, I have a very understanding employer in the city of Emmendingen and can work a lot in my home office. That's the only way it works.

The reaction at my former employer Gegenbauer (until 2013) was also incredibly positive for us when they learned about our difficult situation 1 ½ years after I left. Many former colleagues did a lot for us. My former boss organized a fundraising campaign, for example. Hundreds of companies with many thousands of runners take part in the „Berlin Company Run“ through the Tiergarten (a very large park). In 2015, all Gegenbauer runners wore these T-shirts:



„I run for Jonas and all other ME/CFS sufferers“

9. Why doctors hold on to wrong beliefs for so long

In the meantime one reads, hears or sees probably weekly good and detailed publications about ME/CFS in relevant German media like e.g. ARD, national and recognized newspapers or magazines, radio stations etc. By now, all new scientific studies on ME/CFS come to the conclusion that it is an organic and not a psychological disease. Also in civil services, authorities and at our health and care insurance company we always met a lot of understanding for our situation in 2022. Only at the point where it would be most important, there seems to be hardly any rethinking yet: With most doctors, especially in hospitals. How can this be explained ???

Doctors in hospitals often have to make decisions under great stress that can mean life or death for their patients, or at least have a major impact on their future health. When an emergency arrives at the hospital or a patient is on the operating table, there is no time for discussion, but for quick and precise action. This speaks in favor of hierarchical structures.

In Germany, medicine can only be studied by those who have the best Highschool grades, and medical studies can only be mastered by very performance-oriented people. Doctors can therefore not only feel that they belong to an elite, they are an elite in that sense.

Therefore, doctors must be extremely self-confident people, otherwise they would be unsuitable for their profession and could not take it up. The flip side of huge self-confidence can be self-absorption to the point of arrogance. A high-ranking and highly respected physician will hardly be able to admit that he or she was subject to a very fundamental error in treating patients for decades. This was true of other widespread diseases before ME/CFS. Multiple sclerosis was considered a hysterical imagination of women for many years until research found out the real causes of this disease.

10. ME/CFS sufferers could recover quickly if...

... only the right switch is flipped. And research has yet to find it.

The Lyme disease treatment in 2015 (see above chapter "Course of the disease") showed us that the disease did not cause any irreparable damage to Jonas. After half a year of almost complete immobility, it was like after a Sleeping Beauty sleep, like a miracle, when most of the symptoms disappeared or became weaker and his body recovered. Only, unfortunately, not in the long run.

11. Worry about the future ? What could happen...

Of course we hope for an improvement of Jonas' condition and only in this way we can somehow bear the huge burdens over such a long, long time. But: I find it increasingly difficult. We are getting older and the stresses are causing wear and tear on us. The following scenarios could mean big problems at any time:

No care facilities if we fail: In 2020, I had a herniated disc with subsequent surgery and Andrea had to take over most of my care activities despite her own ME/CFS disease and Jonas' younger brother Julian also stepped in. My wife is still suffering from the after-effects of these burdens, which were far too great for her. Since then, her health has seriously deteriorated. We don't know what we would do if I were to fail again. My wife could not replace me a second time. Then Jonas would have to go somewhere else. But there is no facility where even a little consideration would be given to his extreme sensitivities to sensory stimuli. In 2015, our family doctor at the time, Dr. Schwald, assumed that Jonas would not have survived permanent placement in a psychosomatic facility, which at the time was being sought by the University Clinic of Freiburg. At that time, however, he was in worse shape than today.

Power outage: We have acquired a small "prepper" kit for emergencies. Emergency power with power station, durable food, two large gas bottles with stove and heat generation, etc. But it wouldn't last for a prolonged outage.

Fire, bomb or gas alarm: In our apartment in Freiburg, I had to stay in the apartment with Jonas during a gas alarm, although evacuation was ordered at short notice. Our situation in D. is much improved, since we live on the ground floor and got an emergency stretcher with which we could transport Jonas out of the house without outside help. We have also equipped all bedrooms with fire detectors (as it is mandatory by law in Germany but not everybody does). But where should we go with Jonas in case of an emergency?

We persevere in the hope of a breakthrough in research on ME/CFS. So that one day we and Jonas will have a normal life worth living again.



Jonas with Andrea 2012 on La Palma looking towards El Hierro