

The importance of holistic and rapid care in tackling Finland's hepatitis C crisis

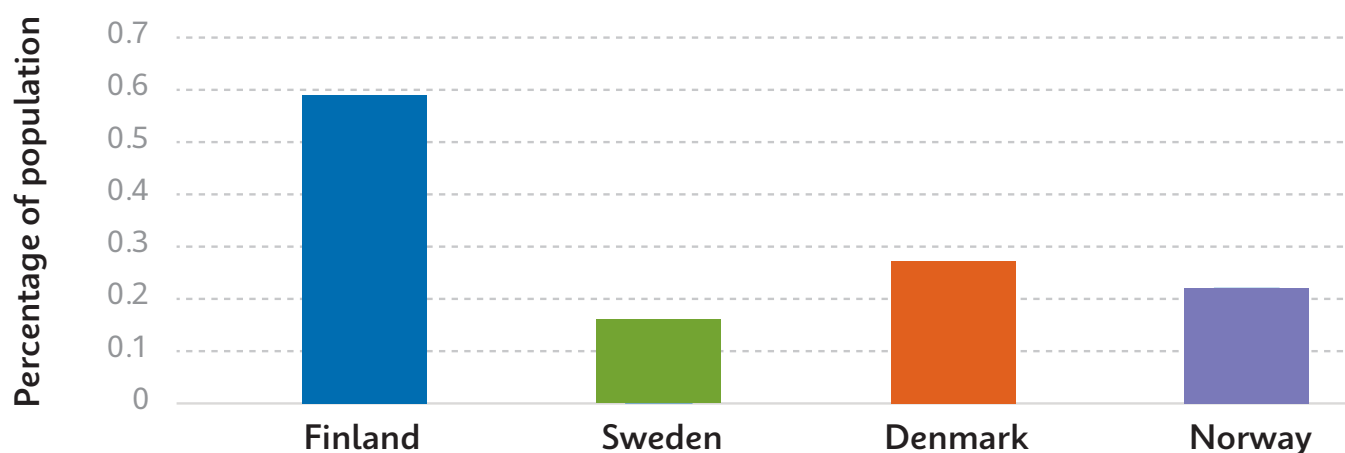
Overview

Hepatitis C, caused by the hepatitis C virus (HCV), is a major public health concern in Finland, with 1,148 new cases reported in 2022, and the majority (33 per cent) in Helsinki and Uusimaa.¹ More than 25,000 people (0.59 per cent of the population) are estimated to have a chronic HCV infection based on 2019 figures,² putting them at heightened risk of developing cirrhosis, liver failure and liver cancer, and creating a significant cost burden for the Finnish healthcare system for treatment costs, hospital stays and advanced liver care. Numbers suggest that this is almost double the prevalence reported in other Nordic countries, which stand at 0.27 per cent or less (Sweden: 0.16 per cent, Denmark: 0.27 per cent, Norway: 0.22 per cent),² however, the cited figures may strongly depend on the availability of testing and reporting. HCV spreads through contact with blood, and needle sharing among intravenous drug users is the most common mode of transmission, responsible for 40 per cent of all cases in Finland.¹ In 2019, Finland was one of the top countries in Europe where the majority of chronic HCV infections were attributed to intravenous drug use, along with Denmark and Austria.² Co-infections with other bloodborne viruses—including human

immunodeficiency viruses (HIV) and hepatitis B (HBV)—are therefore very common, which can increase the rate of fibrosis progression, resulting in liver failure being the most common cause of death in HIV/HCV co-infected patients.³ Given the stigma that follows those who inject drugs, they are often harder to reach and less likely to be accepting of testing and treatment, making this a challenging virus to tackle.

Finland has committed to the World Health Organization's (WHO) objective to reduce the burden of the disease once and for all by eliminating hepatitis C as a major public health threat by 2030.^{4,5} However, the country is still far from achieving this goal, and the number of people newly diagnosed with HCV every year remains steady at approximately 1,150 cases, despite efforts to formulate preventative strategies.¹ Several stakeholders—ranging from an executive director of a welfare service to primary care nurses—gave their perspectives on what initiatives are currently being considered to get Finland on track to reaching the WHO's target. This white paper summarises the findings from these discussions and highlights key recommendations that may improve holistic care of patients with HCV, including the importance of test-and-treat pathways in primary care settings.

Estimated chronic HCV infection²



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Mirka Vainikka

Executive Director at Irti Huumeista ry support service for drug users and their families

Current guidelines for HCV

The Finnish healthcare authorities have proposed several guidelines in recent years with the aim of establishing a harmonised clinical pathway from testing to treatment of HCV across the country. The 2017-19 hepatitis C strategy established several objectives for Finland: improving awareness; harmonisation of testing and treatment; and developing a monitoring system, with the long-term goal of treating all HCV carriers, regardless of the degree of liver damage.^{6,7} The HCV treatment path recommendation was published by the national HIV and hepatitis expert working group—appointed by the Finnish Institute for Health and Welfare (THL)—and shifted treatment from specialised medical care to primary care centres, placing the responsibility on municipalities to provide the necessary resources.⁴ Treatment can now be provided in various locations where testing is offered, including substance abuse services, prisons and welfare centres for intravenous drug users, which is a huge leap forward for Finnish healthcare, as active drug users had previously been denied access to HCV treatment.⁴

Despite these efforts, Finland continues to lag behind many other Nordic and EU countries in implementing HCV eradication strategies, and predictions in 2018 suggested that the country would need to increase its treatment rates 200 fold in order to meet the WHO's goal by 2030.⁸ In contrast, Norway and Denmark would only need to increase treatment rates by six to nine times, and Sweden 17 times, to achieve the same goal. As it currently stands, it is estimated that Finland is approximately 20 years behind this deadline, with dwindling hopes of meeting the target even by 2050.⁹ The healthcare reforms in 2023 divided the country into states,¹⁰ providing the perfect opportunity and timing to reevaluate exactly how Finland can tackle HCV eradication. The current national guidelines aim to instigate a program to eliminate hepatitis C by 2027, and guide the wellbeing services counties to agree on specialist services, collaboration and division of labour in 2024.¹¹ In light of this,

it is clear that further guidance is needed to establish both the funding model and a standardised patient care pathway for HCV, highlighting how the country may move forward with eradication as a united nation.

“Updated HCV guidelines have been postponed for many years as we anticipated the renewal of our healthcare system in 2023, so very little movement was made. The 2019 guidelines were established in an era where our healthcare system was completely different. Now is a good time to bring the welfare areas together and create a strategy that reflects our new healthcare system, developing a united process of decision making for HCV and many other disease threats in the future.”

Dr. Ulrika Sundell

Medical Director of A-Klinikka

At-risk groups

People who inject drugs (PWID)

The largest population at risk of HCV is PWID, and the most affected age group is young people between the ages of 20 and 29.¹² Drug use is a major public health concern in Finland, which recorded the highest number of drug-related fatalities among youths in Europe in 2023, almost 30 per cent of whom were under 25 years old.¹³ Prevalence of HCV in the cohort of PWID is significantly high, with 75 per cent estimated to have antibodies to the virus. The rate of infection is also staggering as a quarter of injecting drug users are infected with HCV within just two years of initial injection, and more than half within five. Since 2004, the Communicable Diseases Act has made it obligatory for municipalities to organise healthcare and counselling for injecting drug users, including public needle and syringe programmes (NSPs), to prevent the spread of disease via injectables. It is likely that this has contributed to the significant decline in HIV and HBV that Finland has experienced in the last decade, however, the prevalence of HCV has remained steady.¹⁴

Considerations for PWID

Extending treatment to this patient cohort requires careful consideration of the needs of the group to create more effective testing and treatment practices. There is still a great deal of stigma that surrounds drug users, and a recent survey by A-klinikka found that the country is very much divided, with 52 per cent of respondents believing that drug users should be considered criminal, while 45 per cent support the establishment of drug use facilities.¹⁵ This stigma often means that PWID avoid hospital settings and struggle to trust healthcare professionals due to previous negative experiences. Patients suspected of HCV may also be treated with more caution to protect healthcare workers, which may be disconcerting. Given their history of intravenous drug use, taking venous blood samples from patients can be very challenging, and they may refuse because of difficulties with their veins.¹⁶ Their motivation for testing and treatment can also be fleeting. It is therefore critical that diagnostic and treatment activities are carried out in such a way that is fast, prevents discrimination, and provides holistic and personalised care, taking into account the knowledge and experiences of each population group or patient.

“When the guidelines changed in 2019, we had a line of patients coming for treatment who had mostly stabilised their drug use, or were in recovery, so they were motivated. Nowadays, we have far fewer motivated patients to take care of, and often they are not able to attend appointments for testing for any infections because it’s difficult for them to go to a laboratory.”

Dr. Henna Rautiainen

Gastroenterologist and Founder of Finland’s HCV helpdesk at HUS Vatsakeskus

Prisoners

The prevalence of HCV among prison inmates is also high, with nearly half infected.¹⁷ One study found that 71 per cent of female prisoners between the ages of 16 and 24 have HCV, which was linked with certain risk behaviours like needle sharing for drugs and unsafe sexual habits.¹⁸ The Finnish national drug strategy in 2016-2019 highlighted the importance of ensuring the availability and quality of drug treatment in prison.¹⁷

Migrants

Migrants are also disproportionately impacted by HCV; a screening programme found 63 per cent of HCV-positive migrants of Kurdish, Russian and Somalia origins had not been previously diagnosed, 70 per cent of whom had been living in Finland for more than five years.¹⁹ THL is currently in the process of updating its guidelines for infectious disease screening for immigrants, and will likely recommend screening for those from countries with high prevalence and those at high risk.¹ The burden of HCV is therefore strongly associated with the intricacies of social, economic and political developments, such as migration, war and drug use.

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Mirka Vainikka

Executive Director at Irti Huumeista ry support service for drug users and their families



The current test-and-treat pathway for HCV in Finland

HCV is a treatable condition, and the key to ensuring patients have access to effective treatment is to provide early and timely diagnosis. This is incredibly important, not only to disrupt the onset of liver damage in patients, but also to prevent the disease from spreading further. The 2017-19 strategy states that access to testing ‘must be harmonised and everyone must be guaranteed unhindered access’.⁷ The move in 2019 towards regional treatment programmes in settings such as primary care, prisons and welfare services for drug users aimed to increase access for all by bringing testing closer to the patient, improving appointment attendance and treatment compliance. This framework is incredibly important because Finland is one of the most sparsely populated countries in the EU, with a very low population density of 39 people per square mile, so distance can be a significant barrier to care.²⁰ The psychological barriers to care can also be far greater because vulnerable patients, such as PWID, are reluctant to seek help in traditional hospital settings. Instead, these regionalised welfare services can provide a continuity of care, as patients can obtain support, counselling, testing and treatment in one familiar location that does not necessarily resemble a hospital.

This model of care works well for managing the range of conditions to which PWID are susceptible. Current guidelines suggest that patients suspected of HCV should be given a sensitive diagnostic test on first presentation and at least 12 weeks after treatment to determine the sustained virological response. Those in opioid substitution therapy are given HCV testing yearly, and inmates are tested on arrival at the prison. However, given the risk of comorbidities, the WHO recommends triple testing for HIV, HBV and HCV, which could help to identify infections that

would have previously gone undetected.²¹ It is crucial to rule out HCV/HBV coinfection before initiating treatment, because the dominant virus—typically HCV—will exhibit virally-mediated inhibition of the other, and its suppression can lead to the reactivation of the nondominant virus.²³ In Finland, positive HCV patients are tested for HBV, as a positive result would influence treatment plans. Adding HIV testing to the mix also helps, and providing all three tests together can contribute to reducing drop-out rates, by minimising the need for repeat appointments.

The current gold standard method of testing is the detection of serum antibodies to HCV, which is often fast, amenable to point of care (POC) and inexpensive. However, any positive results from serum antibody tests must be followed up with a nucleic acid assay to determine whether the chronic infection is present or has been spontaneously cleared. In addition, antibodies can still persist in a patient’s bloodstream after treatment, but a negative nucleic acid assay can confirm that the patient is no longer infectious, regardless of the antibody result. Historically, nucleic acid assays were largely accessed through centralised laboratories, which would require either referring patients to the laboratory to provide intravenous blood samples or sending patients’ samples from the primary care setting. The laboratory would then run the test and return the results in approximately two to three days, where patients would access them—and any treatment—through primary care or welfare centres. However, this test-and-treat pathway relies on patients returning for multiple appointments in different locations, which is often not practical and extremely hard to coordinate, leading to a high dropout rate of approximately 40 per cent. It also creates a gap in the continuity of care between laboratories providing testing and those administering the treatment, which can lead to inefficiencies.

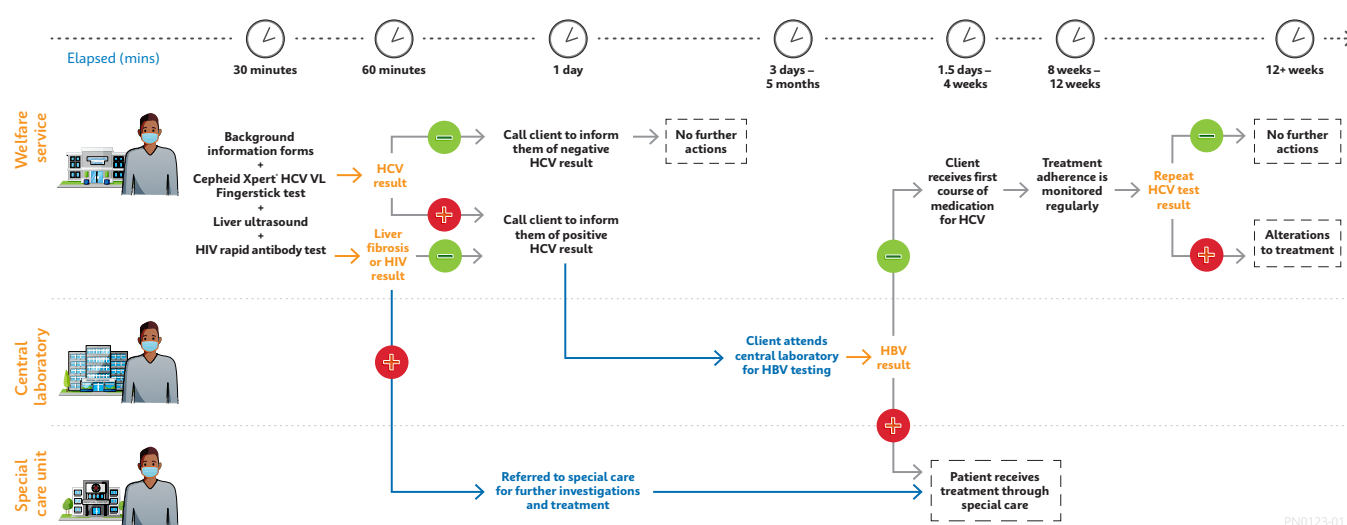


Figure 1: A suggested pathway for HCV testing in welfare centres based on expert recommendations, which could significantly reduce the opportunity for patient dropout

“Often, customers want to be tested at our centre for HCV [rather than the public laboratory]. This is also good for us because we wouldn’t know the result of the test [from the lab] unless they told us. Whereas, if we do the testing, we can understand the sustained virologic response and how effective the treatments are that we are giving.”

Sanna Lappalainen

**Head Nurse; Laura St. Clair, Social Care Worker; and
Lea Lehmuskoski, Nurse at the NGO ViaDia Lahti ry,
Terveysterveystapiste Jelpi**

Rapid, POC nucleic acid tests [such as the [Cepheid Xpert® HCV VL Fingerstick](#) test on the GeneXpert® system] remove the need to refer patients to an external laboratory for HCV testing, and enable nurses to return results on the same day. Patients can also access HIV rapid antigen testing, as well as a liver ultrasound, at these locations, so that clinicians can immediately instigate treatment plans following further testing for HBV in a central laboratory. Samples can also be taken from fingerpricks, reducing the dropout rate from those who are fearful or unable to provide blood intravenously. Keeping the entire process of HCV, HIV, and liver examination in one setting and to minimal appointments may also decrease the risk of dropouts from patients who struggle to visit external laboratories multiple times. Häkkinen, et al. found that opioid users preferred this method of POC to conventional hospital-based blood testing.¹⁶ However, in Finland, HBV and AST platelet ratio index (APRI) testing are still under the domain of central laboratories, so patients are required to attend a laboratory, although some welfare centres are able to take blood draws locally and send them on to the testing location. Typically, the largest drop out occurs when people need to attend a laboratory for HBV testing. THL aims to introduce an HBV antigen test in the future, which would help to minimise the bottleneck created by this pathway and hopefully reduce testing dropout rates even further.

Recommendations for the future of HCV pathways

Holistic healing

Bringing accurate and comprehensive testing to the point of patient care in this way supports the concept of a truly holistic healthcare model. Testing and treatment for HCV in PWID is most effective as an integrated approach that considers pharmacotherapy, psychiatric and social interventions,²³ as well as comorbidities. A ‘one-stop shop’ should significantly increase the efficacy of treatment, by not only healing the liver and the initial infection, but also helping to prevent re-infection rates by curbing drug use.

“Of course, we have to treat each person as a whole human and face the humanity in the patient. I think that we have been developing our healthcare system towards this, in both somatic healthcare and the psychiatric field.”

Dr. Jyri J. Taskila

Chief Medical Officer at Lapha

Location

Ideally, this holistic healthcare should take place in a location that is both familiar and trusted by PWID. Since 2019, welfare services, such as needle exchange locations, have provided important, local safe havens for PWID where they can seek testing and treatment without judgement. Previously, patients would have to visit special care services, which can often be located great distances from where the patient resides. Performing rapid and sensitive POC nucleic acid tests in local settings is critical to bring everything closer to the patient, avoiding repeated visits to a laboratory and improving compliance to treatment and monitoring. To reach those in the wider community, services are also considering using advocates of testing or coaches who can communicate the importance and the safety of testing to others; they are far more likely to attend a new setting if they have seen their friends or family succeed.

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Laboratory testing is tricky for the patient as they have to attend the laboratory to give their blood intravenously. POC testing means that customers can have their test results on the same day. The difference is that if they hear the result in an hour, they can feel that their situation is being taken care of, whereas the result from the lab can take several days. [...] We always advise patients to come for testing when we have a Cepheid GeneXpert system available.”

Sanna Lappalainen

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The biggest change in the last ten years is that patients can get tested out in the community, rather than in a specialist hospital. Patients are far more likely to attend a local centre, especially when you consider that in a region as large as Lapland there are only two hospitals.”

Dr. Jyri J. Taskila

“Trust is always the biggest issue. [...] It is much easier to convince a PWID to commence treatment if they are already attending a welfare centre, it's the people who are not who are harder to reach.”

Mirka Vainikka

Removing stigma and increasing awareness

Removing the stigma surrounding drug use is still a top priority, as this goes a long way towards encouraging PWID to trust healthcare settings for HCV testing. This can be achieved by increasing awareness of the issue and sharing personal stories that highlight the perspectives of PWID and their families. In addition, it is important to always communicate the consequences of not taking treatment to HCV carriers or infected patients, to encourage them to seek and comply with treatment.

“We have a lot of patients, who have either had an addiction or have a loved one with an addiction, working with us to develop campaigns with their stories and their faces to help remove stigma in the future.”

Mirka Vainikka

“There will always be patients who do not want treatment, but we must think about motivating them. We must talk to them every time they attend an appointment, just continue to have a conversation with them to discuss any issues without judgement again and again, and only then will we have an effect on them.”

Dr. Jyri J. Taskila

“HCV is strongly associated with people coming from lower economic backgrounds. I think we would have already eradicated it if we considered it a disease that can spread amongst everyone. In reality, it's not just one part of the population that is impacted. It does affect PWID, but also newborns with an infected mother or partners of those who may not have realised they are infected. It will soon affect even more people if we don't treat it and prevent its spread. That's the message I really wish people would hear.”

Dr. Ulrika Sundell

Innovations

Innovative initiatives that bring testing closer to the patient, such as mobile POC testing units, are an important step forward to reach a wider cohort and increase access to healthcare, by bridging the gap between services and the community. Again, it's important that testing is rapid in order to provide patients with results on the same day—within the same appointment even—while they are willing to access testing and treatment. Research has found that treatment initiation is faster with onsite POC testing compared to laboratory-based POC assays or standard-of-care (SOC) assays, and treatment uptake is significantly higher with onsite POC (77 per cent) and mobile POC assays (81 per cent) compared to SOC (53 per cent).²⁴

Funding

The biggest barrier to instigating any new form of guidance or testing is always funding. As it stands, there is simply not enough funding for every welfare centre to implement rapid POC testing in Finland. This is likely because there is still a lack of awareness of the cost and consequences of HCV on the nation, and population- or municipality-wide research would certainly help to fully understand the benefits of POC. At a global level, several studies have already highlighted the cost-saving potential of POC testing that comes from diagnosing HCV infection in a single visit,^{25,26} simplifying the cascade of care and improving the diagnostic rate. Detecting infections early also clearly saves on costs, by preventing cases from advancing to liver disease and avoiding the expense of specialist liver care. This is incredibly important as the health economic burden of HCV-induced diseases across Europe is staggering when factoring in treatment, hospital stays and advanced liver care, costing an estimated 1.06 million Euros in Italy,²⁷ for example, including both indirect and direct healthcare elements. This total cost is likely to be higher in Finland, when factoring in the high prevalence and the cost of drugs, which is approximately 5,000 Euros. Not treating the initial infection early enough frequently leads to further expense, as shown by a study in the US that found that immediate treatment of acute HCV was more cost-effective by preventing the risk of transmission and improving clinical outcomes.²⁸ These examples demonstrate that any concerns over the cost of implementing POC testing can be easily offset against the potential savings that could be made further down the patient pathway.

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Funding is the most important issue, but also how we do it. We should make a step-by-step plan of exactly how we will tackle HCV to meet the WHO's eradication goals.”

Mirka Vainikka

In Finland, the possibility of a more cost-effective approach coincides with recent reforms to the healthcare system that provide the perfect opportunity to reevaluate how funding will be designated to each welfare state. The previous system gave autonomy to different cities, so funding to welfare services often depended on the economic planning and guidelines provided by the governing body in that area, creating significant discrepancies across the country. Moving forward, it is essential that there is more cooperation between each division to work toward the shared goal of eradicating HCV.

“It is really important for the people in charge of each welfare state to come together around the same table to create a plan. Currently, the welfare system is very scattered and the biggest issue is always who should pay for testing and treatment [particularly when patients move across borders]. Instead, there should be one pot of money designated to the issue of HCV that is divided fairly between states, and each state should declare how it will spend this money for HCV. We should not be seeing this as ‘these are my patients and this is my budget’, but instead this is an effort that belongs to all of us. This change is essential for everyone to move in the same direction.”

Dr. Ulriika Sundell

Guidelines

The current Finnish guidelines for the HCV test-and-treat pathway emphasise the importance of treating everyone, regardless of the extent of their liver damage. It is hoped that new guidelines expected in early 2024 will recommend the harmonisation of rapid testing and treatment in all centres, providing a clear guide to standardised care. These guidelines should be drawn up with stakeholders from each welfare state, creating a unified approach to HCV eradication.

“The current pathway states that we should treat everyone regardless of liver damage, but it doesn't specify how.”

Dr. Henna Rautiainen

“I think there is still a need for slight differences in testing between each location, but there should be more standardisation. There should be three or four different universal ways of testing defined by the guidelines, and then each area can select the method that serves them best.”

Dr. Ulriika Sundell

Conclusion

Changes to the Finnish public healthcare system in 2019 have gone a long way to improve the accessibility of HCV management by empowering welfare services to provide treatment, keeping it all under one roof. However, with the new healthcare reforms, the national goal is to now formulate a plan as to how the country will move forward and delegate responsibilities and funding. To reach the WHO's target of eradicating HCV as a public health threat by 2030, the welfare states need to work together to develop an action plan with detailed and well thought out guidelines for testing and treatment, as well as allocate funding where it is needed most. Currently, most services still rely on laboratory testing, which often discourages patients from taking advantage of the comprehensive testing and treating service that is being offered. Rapid, POC testing would help to eliminate this hurdle, by providing results to patients on the same day and in local settings. As the country anticipates a new set of HCV guidelines, emphasis should be given to treating patients holistically and implementing rapid testing as a means to instigate treatment sooner and prevent the spread of HCV in the future.

“We need to put HCV on the priority list, so that we don't give the burden to our children, who will be left to deal with the disease that we didn't want to—or understand how to—eradicate when we had the chance. This is something that I wish decision makers would really understand and see that it's best for all of us, not just those who have the disease now, but also those who might have the disease in the future. To me, it's also really important to consider how this might even affect other species if we continue to let the virus spread; we saw with COVID how quickly viruses can evolve high levels of virulence when let loose.”

Dr. Ulriika Sundell

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