



SA TALLINNA LASTEHAIGLA



## Child Health International: Wales - Estonia collaboration

### Historic visits

- 2009 The Cardiff-Estonia Program within CHI commenced in 2009 with a visit by Dr Iolo Doull from the Children's Hospital for Wales to Tallinn and Tartu. Connections were made with Dr Urve Putnik in Tallinn and Dr Maire Vasar in Tartu.
- 2014 In Spring 2014, Dr Urve Putnik and Dr Maire Vasar visited Cardiff, attended the Children's Hospital for 4 days with Dr Julian Forton and attended a State-of-the-Art Symposium on Cystic Fibrosis in London.
- 2014 In October 2014 Dr Julian Forton and physiotherapist Natalie Gragosin from The Children's Hospital for Wales visited Tallinn and Tartu, giving talks on Physiotherapy and attending clinics in both cities.
- 2017 In Spring 2017 a reciprocal visit to Cardiff was arranged for medical, physiotherapist and dietetic staff from both Tallinn and Tartu. The visitors were Dr Tiia Voor, Karin Tammik (physiotherapist) and Siret Saarsalu (dietician) from Tartu, and Dr Karin Puks, Margit Juudas (physiotherapist) and Liina Heinvere (dietician) from Tallinn. The team shadowed the CF service attending annual assessments and outreach clinics and interacting with their therapy partners.

Since 2017 there has continued to be regular email communication between Prof Julian Forton and Estonia, particularly with Dr Maire Vasar in Tartu. Children with CF and also other children with respiratory disease have been discussed, and the interactions have been very useful through the COVID pandemic.

### Developments in Cystic Fibrosis Care

Over the last 6 years there have been many positive developments in the treatment of children and adults with Cystic Fibrosis, and these are particularly related to the development and implementation of highly effective modulator therapy. 4 modulator therapies exist: Ivacaftor, Orkambi, Symkevi and Kaftrio. Each of these have specific licenses for use, which are dependent on the patient's genetic variants and patient age. The impact of these treatments on respiratory morbidity has been transformational for a majority of patients. Currently there is an effective modulator treatment with license available for 94% of patients with CF. Availability and funding of modulator therapy varies across nations. Currently Estonian patients with CF do not have access to these medications, except through charitable or self-funded means.

### Developments in Cystic Fibrosis Care in Estonia

Whereas previously there were 2 centres for CF care in Estonia based around the Paediatric Departments in Tallinn and Tartu, there are now 4 centres for CF care in Estonia with an evolution in adult CF care.

#### *Paediatrics*

- Tallinn Children's Hospital [SA Tallinna Lastehaigla]
- Children's Clinic, Tartu University Hospital [Tartu Ülikooli Kliinikum]

#### *Adults*

- Pulmonary Clinic, North Estonian Regional Hospital  
[<https://www.regionaalhaigla.ee/en/pulmonoloogiakeskus-eng>]
- Pulmonary Clinic, Tartu University Hospital  
[<https://www.kliinikum.ee/en/clinics-and-services/clinics>]

There are no specialized CF clinics or Departments in Estonia. CF patients are treated in paediatric or in pulmonology wards by paediatricians or pulmonologists.

## Staff

### Tallinn Children's Hospital

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Medical team:	Drs Silvi Pladi (Head of Service), Karin Puks, Kadri Muoni and Siiri Paas Dr Urve Putnik is retired but still involved in the service.
Nurse:	Kairi Nigul
Physiotherapist:	Christina Lõokene

### Children's Clinic, Tartu University Hospital

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Medical team:	Drs Maire Vasar, Tiia Voor (Head of Centre), Kaja Julge, Anneli Viidebaum
Nurse:	Tiiu Vaher
Physiotherapist:	Karin Tammik

### Northern Estonian Regional Hospital (Adults):

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Medical team:	Drs Liina Viks, Martti Jaanus
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### Lung Clinic of Tartu University Clinic (Adult):

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Medical team:	Drs Marget Savisaar, Nastja Kamõnina, Viktoria Ivanova
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## System of Healthcare and funding for Cystic Fibrosis

- Health insurance is organised by the Estonian Health Insurance Fund (EHIF) and its 4 local departments. The Estonian Health Insurance Fund is the only organisation in Estonia dealing with compulsory health insurance. All health services for insured persons are paid to the health care institutions by the Estonian Health Insurance Fund.
- All health services (inpatient stay, outpatient visits, diagnostic examinations) are covered by the EHIF for patients with Cystic Fibrosis.
- Not all medicinal products are compensated by the Estonian Health Insurance Fund but the following are compensated for patients with cystic fibrosis at the following rates:
  - 100%: all inpatient medicines registered in Estonia
  - 100% : enzymes, ACC, Pulmozyme, ciprofloxacin, nebulized TOBI, TOBIPodhaler, azithromycin, 2 bottles of Nutridrink per day
  - 50%: salbutamol, asthma medications
  - 50% : ursodeoxycholic acid [100% for liver fibrosis]
  - 50%: other antibiotics [100% reimbursement for children < 4 years old]
  - 0%: Vitamins; 5.8% hypertonic saline

## Funding for Modulator therapy

- Kaftrio price negotiations between EHIF and Vertex Pharmaceuticals have not been successful to date. Negotiations have been going on for 2 years.
- Kaftrio is registered in Estonia, and the patient can buy the drug at full price.
- EHIF does not reimburse for Modulator therapy. Of the current cohort of CF patients in Estonia, three children receive modulator therapy with independent funding (Tallinn's Children's Hospital Foundation and Tartu University Hospital Children's Foundation). Three adult patients receive treatment intermittently with the support from donations made through the media and through self-funding. One adult is using non-proprietary Kaftrio obtained online (apparently from Greece). One family has moved to Finland to obtain modulator therapy.

## MDT working in Paediatric clinics

- Resources for a structured MDT team is improving.
- All CF patients (children and adults) receive nutritional counselling by dieticians who have received professional training.
- Physiotherapy is available to everyone, although not all physiotherapists have received CF-specific training. Physiotherapist Karin Tammik in Tartu Children's clinic is highly experienced, but experience in Tallinn Children's hospital is currently less strong now that Margit Juudas has retired.
- Psychology is not widely available, but a psychologist has started working at the Tartu Children's Clinic and is interested in taking on CF.

## Service structure for Paediatrics

- **Outpatient facilities** for children with CF are established with paediatric pulmonology specialists and the limited MDT at the Allergy Centre in Tartu and Allergy and Pulmonology Service in Tallinn. There are no specialist clinics for CF in Estonia since numbers are small. Patients are seen in separate clinics from each other to minimise the risk of cross infection. There are routine quarterly follow up visits and short notice reviews when required. There is no formal annual assessment
- **Inpatient facilities** are provided for children with CF on the general paediatric wards or acute infection wards in Tallinn and Tartu. Parents can stay with their children. Food is provided for patients and in Tallinn, for parents as well. Care is delivered by paediatric pulmonologists and/or the attending paediatrician for the ward.

## European Cystic Fibrosis Society Patient Registry (ECFSPR)

In June 2023, approval was received from the Ethics Committee of the University of Tartu to start creating the Estonian CF Register and to join the European Cystic Fibrosis Society Patient Registry (ECFSPR). Data from 2022 onwards will be forwarded to ECFSPR.

There are currently 60 patients in Estonia with Cystic Fibrosis

- 0-6 y – 9 children (13%)
- 6-12 y – 12 children (20%)
- 12-18 y – 13 children (21%)
- ≥18 y – 28 patients (46%)

## Newborn screening for cystic Fibrosis in Estonia

All children born in Estonia are offered screening for the following congenital diseases:

- Cystic fibrosis (pilot project 2023)
- Spinal muscular atrophy (pilot project from May 2022)
- Galactosemia
- Congenital hypothyroidism (CSHT)
- 19 treatable inherited metabolic diseases (Tandem MS).

The CF screening pilot project was commenced in Spring 2023 and follows the following algorithm.

- IRT test: DELFIA Neonatal IRT kit performed on the Victor2D device
- PAP test: MucoPAP-F test kit (Dynabio), performed on the Victor2D device
- DNA analysis:
- Sanger sequencing to determine F508del and 394delTT
- Whole CFTR gene sequencing (NGS)

The pilot is being run by Dr Tiina Kahre at the University of Tartu and is financed by the Children's Foundation of Tartu University Hospital. Outcomes will be assessed after one year and decisions made as to whether CF screening is given funding by the Estonian Health Insurance Fund, to be included in the national newborn screening programme.

## The Estonian Cystic Fibrosis Society (ECFS)

ECFS was established in 1998 and is a pan-Estonian, voluntary, non-profit association of CF patients, their relatives and all other persons interested in CF. In total, there are 200 members, including CF patients, their family members, doctors, physiotherapists, etc. There are 5 people in the board – one CF patient and 4 parents. The chairperson is **Madli Kadajas**.

In September 2023, the first joint Meeting for Cystic Fibrosis across the Baltic countries was held in Kaunas, Lithuania, fostering stronger links between specialists.

## CHI Visit to Estonia October 2023

In October 2023, Prof Julian Forton, Katherine Ronchetti (physiotherapist) and Hannah Morgan (physiotherapist) from The Children's Hospital for Wales, reignited the Wales:Estonia collaboration with a 4 day visit to Estonia (9-12<sup>th</sup> October).

### Tallinn

The Welsh contingent were welcomed by Dr Silvi Plado, Dr Karin Puks and Dr Urve Putnik for Dinner on the evening of 9<sup>th</sup> October in Tallinn Old town. Dr Plado is Clinical lead for the CF service. Dr Karin Puks visited Wales in 2017. Dr Urve Putnik has now retired but remains active within the service. She and Dr Maire Vasar from Tartu initiated the CHI collaboration and visited Wales in 2014. Time was spent catching up and discussing new developments in the care of people with cystic fibrosis (pwCF), and constraints in delivering CF care in Estonia.

The next morning the Welsh group visited Tallinna Lasthaigla (The Children's Hospital, Tallinn).

- The team were given a tour of inpatient and outpatient facilities, including lung function facilities and physiotherapy spaces. Infrastructure is very impressive.
- This was followed by 2 lectures delivered to the department. The first was given by Dr Silvi Plado on the current provision and well being of patients with CF in Estonia, highlighting important developments including new potential trans-Baltic collaborations in CF care, a pilot newborn screening programme for CF which commenced in Spring 2023, current funding strategies and the urgent need to establish funded access to modulator therapy for pcCF living in Estonia. The second talk was given by Prof Julian Forton concentrating on outcomes from modulator therapy, potential new treatments, the use of sputum induction in infection diagnostics and the CF-HomeSpIT trial that is being run in Cardiff.
- The team were joined and welcomed for lunch by the Head of Paediatric Clinic at Tallinna Lasthaigla, Dr Reet Raukas.
- After lunch, Kath and Hannah teamed up with the local physiotherapists, led by Christina Lõokene and students to problem solve over physiotherapy issues and demonstrate the sputum induction procedure on 2 patients with CF who had been asked to attend especially. Both patients managed to produce a successful sputum sample. Prof Forton and Drs Plado and Puks discussed difficult clinical scenarios that had arisen in the CF cohort including management of chest exacerbation, eradication therapy protocols for pseudomonas eradication and the use of steroids in chronic productive cough.
- This day together was extremely productive, fostering strong links and exchange of ideas.
- The Welsh contingent left at 3.45 to catch the train to Tartu.

Dr Urve Putnik, Hannah Morgan, Kath Ronchetti, Prof Julian Forton, Dr Karin Puks, Dr Silvi Pladi; Tallinn



Tallinna Lasthaigla Tallinn Children’s hospital



Kath Ronchetti and Hannah Morgan with Christina Lõokene demonstrating the sputum induction procedure; Tallinn



## Tartu

The Welsh contingent were welcomed by Dr Maire Vasar, Dr Tia Voor, Dr Kaja Julge, Dr Anneli Viidebaum, Karin Tammik and Dr Tiina Kahre on the morning of the 11<sup>th</sup> October at the new Children's Hospital at Tartu Ülikooli Kliinikum (Tartu University Hospital).

Dr Maire Vasar initiated the collaboration with Wales with Dr Urve Putnik from Tallinn, and visited Wales in 2014. Dr Tia Voor is the Head of Centre, and visited Wales in 2017. Karin Tammik is an experienced CF physiotherapist and visited Wales in 2017.

The Children's Hospital is a fantastic new facility for Children in Estonia, with 100+ beds, providing specialist services for children across Estonia.

- The team were given a tour of inpatient and outpatient facilities, including lung function facilities and physiotherapy spaces. The facilities are world class, and beautifully designed.
- This was followed by a lecture Prof Julian Forton again concentrating on outcomes from modulator therapy, potential new treatments, the use of sputum induction in infection diagnostics and the CF-HomeSpIT trial that is being run in Cardiff. The large audience included students and trainee doctors from the hospital.
- Dr Tiina Kahre from genetics has initiated the first pilot for newborn screening programme (NBS) in Estonia which started in Spring 2023, and she attended the lecture with her lab technician. The NBS programme was discussed with Prof Forton who agreed to put Dr Kahre in contact with the head of NBS for Wales, Prof Stuart Moat, to help optimise the assay in Tartu and help solve any technical issues that may arise.
- Lunch was provided in the hospital restaurant.
- After lunch, Kath and Hannah again teamed up with the local physiotherapists, led by Karin Tammik, who they had met before when she visited Wales in 2017. Sputum induction was again demonstrated and facilities, physiotherapy aids, nebulisers and resources were all discussed. Prof Forton again discussed difficult clinical scenarios with the medical team.
- The hospital work was followed by a tour of Tartu by car, including other hospital facilities courtesy of Dr Kaja Julge. The Welsh team were given a guided tour of the Estonian National Museum, and invited for dinner with the Team from Tartu.
- The Welsh contingent left Tartu on the morning of 12<sup>th</sup> October to return to the UK.

The Children's Hospital @ Tartu Ülikooli Kliinikum (Tartu University Hospital).



Prof Julian Forton delivering a lecture on modulator therapy and sputum induction trials, Tartu



Hannah Morgan with Karin Tammik demonstrating secretion clearance manoeuvres using PEP and exercise, Tartu





Dr Anneli Viidebaum, Dr Tia Voor, Dr Maire Vasar, Karin Tammik, Prof Julian Forton, Dr Kala Julge, Hannah Morgan, Kath Ronchetti



## Reflections and action points from October 2023 visit to Estonia

The visit was recognised as extremely useful by both the Welsh and Estonia teams, with great opportunities to foster links, share clinical and technical advice, develop ongoing relationships and continue to nurture and maintain specialist skills in future professionals.

Issues highlighted as important during conversation with Estonian colleagues centred around the following

- Lack of access to modulator therapy in Estonia
- Technical support for newborn screening trial currently open in Estonia
- Maintaining skills in multidisciplinary team, as staff change over time, and the need for ongoing MDT collaboration.
- Reciprocal visit to Wales in Spring 2024 (Doctor, Physiotherapist, Nurse)
- Solidifying the collaboration between Wales and Estonia through forthcoming ECFS partnership programme