



**Edinburgh
Children's
Hospital Charity**

Families on the brink: Addressing the financial cost of having a child in inpatient or outpatient care

ECHC is calling on the next Scottish Government and all policy makers in the new Scottish Parliament to expand the Young Patients Family Fund so it:

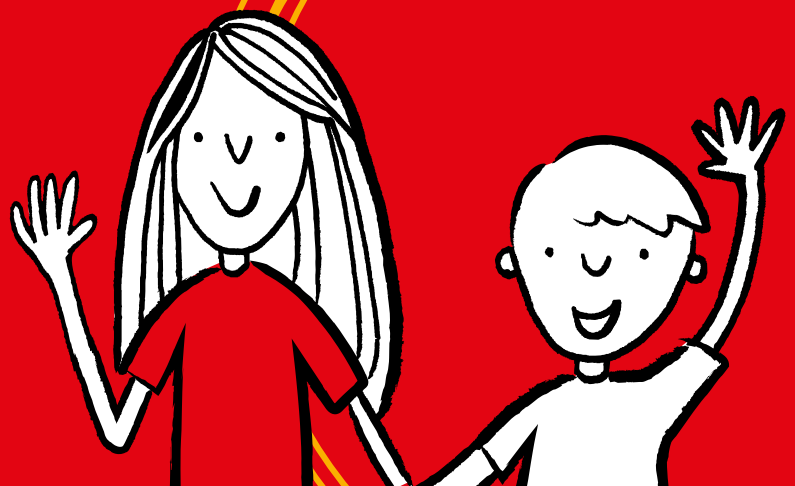
1. Provides a cash-first approach

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2. Includes regular outpatients

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The current system is failing families. Parents already stretched to the limit are being pushed into a deeper financial crisis by reimbursement policies that ignore the realities of everyday life.



Cash first, because reimbursement doesn't work

Too many families simply can't afford to pay upfront for travel, food, or accommodation - let alone wait weeks to be reimbursed. For some, the money never even reaches them. Why? Because it's swallowed by overdrafts or used to repay public debts the moment it hits their account.

And what about the families who can't navigate the complex claims process? Or who don't have a bank account? Or those who are self-employed and lose income every time they take time off to care for their child? For them, cash first isn't a preference - it's a lifeline.

Don't forget the outpatients

It's not just hospital stays that cost families. Children who need frequent outpatient care - like chemotherapy or treatments for chronic conditions such as Crohn's - often attend more than five appointments a year.

That's five days of missed work. Five days of travel costs. Five days of disruption to school, siblings, and family life.

Parents are telling us: they're exhausted, financially drained, and unsupported. Yet the system offers no help unless their child stays overnight.

This isn't right. This has to change. Covering travel and food costs - up front - would ease the pressure and show families that policy makers understand their reality.



Why this matters:
Kobi's story
told by his parents,
Kirsty and Daniel

Kobi was born at 29 weeks, weighing just 3.3lbs. For a brief moment, he seemed to be doing well. Then, in the middle of the night, doctors came pouring into our hospital room.

Our baby's tiny lung had collapsed. He wasn't breathing. And then, the news that changed everything – he'd had a grade 4 brain bleed, the most severe kind. He wouldn't have any quality of life, they said. We should prepare for the worst, call our family in.

*We still hadn't held our baby.
Now, we were being told to say goodbye.*

Against all odds, Kobi pulled through. Eight agonising days later, we finally got our first cuddle. It felt like a miracle. Still, the battles kept coming. Kobi developed meningitis. Each day brought a new fear: blood transfusions, lumbar punctures, MRIs. He was having up to 10 seizures a day. We were always panicked, always so scared for him. We still are.

Eventually, we got a diagnosis: hydrocephalus – a dangerous build-up of fluid on the brain. The only option was brain surgery, to install a shunt. This was just the beginning. Since then, our boy has endured sixteen surgeries. Sixteen times we've handed him over, not knowing if he'd come back.

Caring for Kobi is the greatest privilege in the world. But it's *exhausting and relentless*. And it's such a *lonely journey*. We don't remember the last time we felt at ease, content. We used to have little bits of ourselves outside all this – football, the gym. Now, we go days without having a shower. Sometimes, you wish someone would ask, 'But how are you?'

When the fear feels *overwhelming*, his smile pulls us back. As a family, we can count on one hand the number of days we've had out together. That's all we want – more time, more chances to make memories. We hold on to the hope that one day, this will be possible.

And the *financial strain* is crippling. Living in and out of hospital, travelling back and forth to East Lothian, paying for food, taxis, the upkeep of a house we barely see. *Our savings are vanishing*. And it's likely we'll never work again.

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