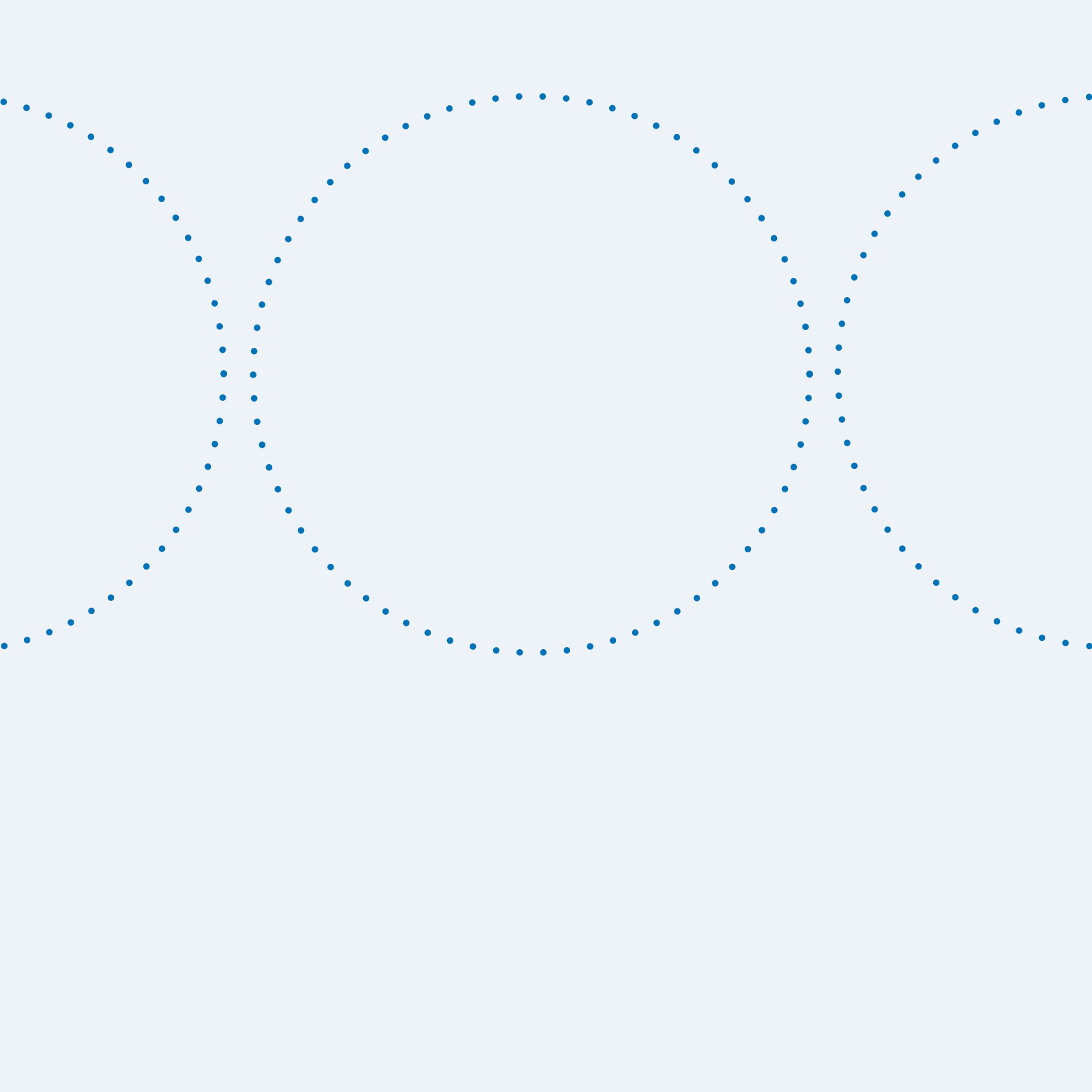




NEWBORN SCREENING

celebrating 50 years in Victoria

1966-2016



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FOREWORD

Professor Kathryn North

Dr Robert Guthrie, developer of the first newborn screening test once said ‘no child should die or suffer disabilities if a simple blood spot can prevent it’.

In 1963, Guthrie and team ushered in a new era in science and public health, developing a screening test that could offer hope and treatment to families grappling with phenylketonuria (PKU).

After newborn screening commenced in Victoria in 1966, we have seen continual advances and improvements in the technology, and today within Victorian Clinical Genetics Services (VCGS) we can screen for 25 different conditions in newborns.

With 2016 marking the 50th anniversary of newborn screening in Victoria, it is timely to remind ourselves that newborn screening is one of the most important public health achievements of the 20th century.

It brings great satisfaction to myself, and the scientists, clinical and laboratory staff within VCGS to know that we are playing a vitally important role in detecting life-threatening and life-altering conditions in newborns across our state.

Hundreds of lives have been saved or transformed as a result of the humble ‘Guthrie card’ and throughout this book you will hear from people whose lives have been impacted as a result of our work.

As we look back at what has been achieved through newborn screening to date, we will also look to the future and the important role newborn screening will continue to play in medicine and research. Research conducted at Murdoch Childrens Research Institute (MCRI) is helping us to understand the incidence and progression of the disorders detected by newborn screening in order to fine-tune treatments and the advice given to parents.

MCRI research studies are now being conducted to develop and assess new screening tests and pilot studies for fragile X, Angelman and Prader Willi syndromes. 50 years ago we could not have imagined what newborn screening is now able to offer us and I am truly excited about what we can achieve in the next 50 years through testing this simple ‘blood spot’.

*Professor Kathryn North AM
Chair, Victorian Clinical Genetics Services
Director, Murdoch Childrens Research Institute*



“I am truly excited about what we can achieve in the next 50 years through testing this simple ‘blood spot.’”

INTRODUCTION

Newborn screening

Newborn screening is an incredibly successful public health program that is conducted worldwide. Each year, millions of babies are screened at birth for a range of rare, but serious medical conditions. These conditions can affect normal development, and identifying them early means they can be treated or managed.

Most parents have little or no recollection of the few drops of blood collected from their child in the first few days of life for the newborn screening test. This is as it should be: for the vast majority, no news (a normal newborn screening result) is good news.

But for the very few who do receive an abnormal result (about one in 1000), this news makes a huge difference to their child's future. Simple treatments can be started early to prevent the permanent damage to the child that would have occurred had this early diagnosis not been made.

Samples collected across Victoria are sent to the newborn screening laboratory, based at The Royal Children's Hospital in Melbourne.


The program is funded by the Victorian State Government and over the last 50 years it has diagnosed hundreds of babies with conditions such as phenylketonuria (PKU), hypothyroidism and cystic fibrosis.

Since the 1960s, the technology used by the program has changed from a simple 'wet nappy' urine test for PKU to sophisticated mass spectrometry technology that can measure dozens of chemical markers for more than 20 different disorders. [No doubt the future will bring equally significant changes, allowing more disorders to be detected through newborn screening.](#)

Dr James Pitt

Head of Newborn Screening Laboratory

Victorian Clinical Genetics Services

A newborn baby with dark hair is sleeping peacefully, wrapped in a pink blanket. The baby's eyes are closed, and their mouth is slightly open. The background is a soft, light-colored surface. In the lower-left corner, there is a blue circular graphic with a dotted border containing the text:

“An incredibly
successful public
health program”

EARLY HISTORY

Newborn screening

To understand the history of newborn screening (NBS), we need to understand the history of phenylketonuria (PKU).

Like most of the disorders detected by modern NBS, this is a recessive genetic condition with a one in four chance that children of carrier parents will have PKU (see Figure 1).

A child with PKU is unable to break down the amino acid phenylalanine which then accumulates in the blood and can cause damage to the developing brain.

PKU was discovered in 1934 by Norwegian Asbjørn Følling who showed its genetic basis and that affected children suffered intellectual impairment. Følling also developed a simple chemical urine test that could be used to detect PKU, known as Følling's test.

In the 1950s, research from Germany showed that a special, low phenylalanine diet could be used to lower the level of phenylalanine in the blood. Sadly, this had few benefits for older children and adults as the damage to the brain had already been done. However, it was found that if the diet was started in the first few weeks of life it prevented the damage and the baby developed normally.

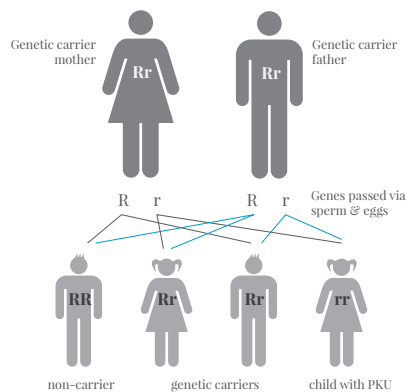



Figure 1. Inheritance of the phenylketonuria PAH gene.
R = normal/working PAH allele/gene
r = faulty PAH allele/gene

Because of the one in four risk to any new babies in a PKU family, it was important to test these babies as soon as possible after birth using Følling's test so the diet could be started. However, most new cases of PKU are 'unexpected': there is no family history, the carrier parents are healthy and there may be unaffected older siblings. Thus, there was a need to test all newborns for PKU.

Early attempts to do this using Følling's test did find 'unexpected' PKU babies but the test was only partially successful. Testing was performed at about two weeks of age, after the baby had been discharged from the maternity hospital.



Parents were required to bring the baby to the infant health centre for testing, which did not always happen. It was also soon realised that the urine test missed a significant proportion of PKU babies.

The next breakthrough came when Robert Guthrie developed a test that could measure phenylalanine levels in a few drops of blood collected onto an absorbent paper card.

This revolutionised NBS because blood testing was much more reliable and the test was simple, cheap and could be used to test large numbers of newborn babies.

Using a dried blood spot card also meant that transport to a central laboratory for testing was much easier. It was later found that the same sample could also be used to test for a number of other disorders.

Although Guthrie's original test has now been replaced, the cards used to collect blood samples are still a critical component of all NBS programs and are still referred to as 'Guthrie cards'.

Dr James Pitt



My story Meet Joseph Karlecik

I was born in 1970 at the Williamstown Hospital. Shortly after birth, I was diagnosed with phenylketonuria (PKU) via newborn screening (NBS).

I grew up in a typical European family with two other siblings. My older brother, Duro Karlecik, was born in the early 1960s, before NBS was widely implemented. He also has PKU, but given his condition was not identified at birth, he is severely intellectually disabled.

After my diagnosis I was put on a special diet for around three years. After that my mother decided she couldn't cope so she stopped the diet and I ended up eating and living like everyone else.

I had no idea I had PKU when I was growing up. It's scary to think about it now and when I look back at my school days, I can see why I struggled at school sometimes. By the time I hit secondary school, I remember attending appointments with a dietitian at The Royal Children's Hospital. I still didn't understand my condition very well and continued living a normal life.

In 1996 I settled down and married a beautiful woman called Jasmina. In 2003 I became a technical assistant at the Murdoch Childrens Research Institute (MCRI) and that same year, my wife and I had our first child, Taliyah.

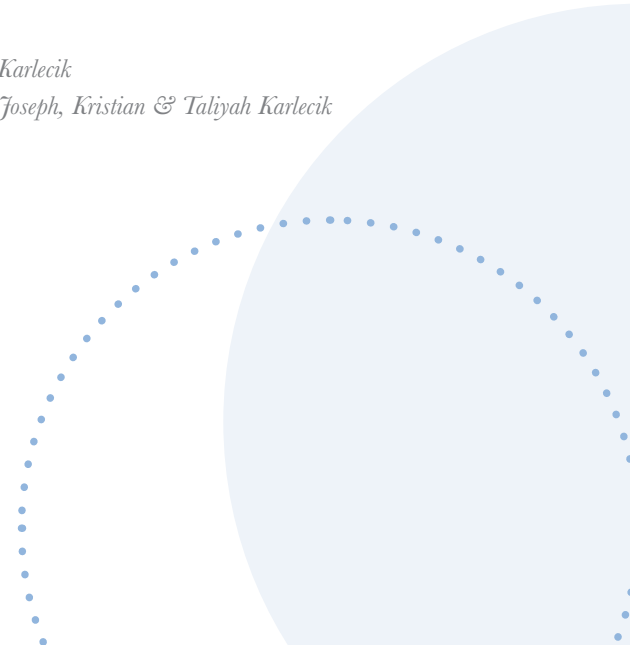
I moved into a new role in the NBS laboratory at MCRI in 2004. A year later, my wife and I welcomed our second child, Kristian.

These days, I'm still working in the NBS laboratory where I have the honour of working in a great environment with a terrific team. I now also have a much better understanding of PKU.

A special moment during my time in the NBS laboratory occurred when I was called upon to speak to a couple with a new baby. Their newborn had been diagnosed with PKU and they were understandably very upset. I told them that I have PKU. We chatted about the condition and about my life, my work and my family. Their smiles returned and it was a moment I will never forget.

Joseph Karlecik

Image: Joseph, Kristian & Taliyah Karlecik



...“I would highly recommend it for all new babies. The few seconds of discomfort is worth it for peace of mind.”



Our story

Meet Annamarie & Ebony Fourie

When you become pregnant for the first time, all you wish for is 10 little fingers and toes, and for your child to be happy and healthy. In our case, two out of three isn't bad. It was thanks to the newborn screening (NBS) program that we were able to find out that our precious little girls, Annamarie (Anna) and Ebony, had inherited cystic fibrosis (CF). With the proper care and support we have been able to raise two healthy, (as healthy as any CF patient can be) little girls.

The actual screening process was nothing overly excessive, just a simple prick on the heel. And in as little as six weeks (at least that was our experience for both our girls) you either hear nothing, which is in itself a good thing, or you get a phone call.

That phone call was horrible to receive. To think that the beautiful little person you call your daughter has inherited something you really wish they hadn't. As Anna's mother, I had to pass the phone over to my partner as I was crying too much to talk. I'm thankful he was there, as I don't think I could've handled that call on my own.

As the newborn test is free for all families there is no real excuse not to get it done. I would highly recommend it for all new babies. The few seconds of discomfort is worth it for peace of mind. Being a new parent, you have that overprotective state of mind and tend to overthink things. The fact that the NBS process is so easy is, in itself, wonderful.

Looking back at photos, especially in comparison, our little girl was so small and bony in the first two weeks of her life, before we received the phone call we hoped we'd never receive. But thankfully we did, and after a few appointments she started looking like your 'everyday' baby. We always thought she was adorable, but now she looked healthy too. As for all the staff and doctors, they were incredibly supportive.

As to my thoughts and feelings towards the NBS program- thank you, just thank you so much for creating this marvellous technique that I'm sure helps a lot of parents sleep better at night (or at least as much as your child lets you!).

Lisa Turner

Image: Annamarie & Ebony Fourie

NEWBORN SCREENING

Introduction of screening to Victoria

The Guthrie test was introduced to Victoria by Dr David Pitt, a pediatrician at Kew Children's Cottages (KCC) and Jan Brasch, a scientist in the KCC laboratory. Initially, testing was performed on patients with intellectual disability as a means of diagnosing unknown cases of phenylketonuria (PKU). During this time the test was moved to the laboratory that serviced the Kew Mental Hospital.

In 1966 I interviewed with David for a job. During this meeting he took me through the landscaped hospital grounds to an old WWII portable building at the rear of the hospital. This two room laboratory shared the building with the hospital pharmacy and surgical unit. The smaller room was set aside for histology; biochemistry, haematology, microbiology and storage were crammed into the larger room.

If I took the job, it was going to be my role to manage all laboratory functions other than histology. Being straight out of university, I could manage the biochemistry, but was entirely ignorant of the techniques required for haematology and microbiology.

Despite misgivings, I accepted the job and managed to cope. I am indebted to the excellent training and support of the ex-paratrooper histologist and the very competent young laboratory technician.

It wasn't long before I was introduced to the Guthrie test. In the original form, this test consisted of an agar culture medium inoculated with a strain of *Bacillus subtilis* (bacterial inhibition assay). This bacterium requires phenylalanine to grow. Phenylalanine is present in excess in the blood and urine of patients with PKU.

Agar medium was poured into Pyrex oven dishes and allowed to set. Dried blood spots were cut out of the cards used for sample collection. These spots were applied to the culture medium and left overnight.

The next day the dish was inspected for bacterium growth. If the concentration of phenylalanine in the patients blood spot was high enough, the bacterium would grow. A high concentration in the blood was an indicator of PKU in the patient.

continued page 16



PKU BLOOD TEST
Write with pencil only:
HOSPITAL:

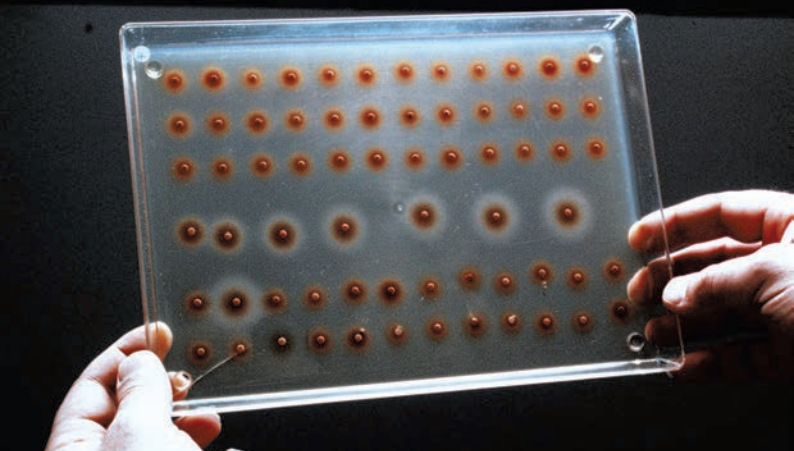
NAME:

Date of birth:

Date of sample:

Referring Doctor:

Doctor's address:



FILL 2 CIRCLES WITH BLOOD
(Be sure blood soaks through)



*Top left: Pouring of the agar plates
Bottom left: Bacterial inhibition assay
Right: The original 'Guthrie Card' for collecting samples*

In 1966, after considerable lobbying from a number of people at The Royal Children's Hospital, the Victorian Government agreed to introduce voluntary newborn screening for PKU. Uptake was gradual and it was several years before coverage of newborns was effectively 100%.

The first couple of years were difficult; only a few abnormal screens were obtained. However, by the late 1960s the program was identifying babies with PKU at the expected frequency.

In 1967 the screening program was moved to a newly constructed complex at Mont Park in Melbourne. In 1991 the program moved to The Royal Children's Hospital in Parkville.

The bacterial inhibition assay developed by Robert Guthrie made population screening for PKU possible. The Pyrex oven dishes and the *Bacillus subtilis* culture medium have now been replaced by \$500,000 mass spectrometer machines and computers that can analyse up to 140,000 results per day.

But Robert Guthrie's legacy lives on in the form of the dried blood spot. While there have been sporadic attempts to replace it, its versatility and practicality has ensured its survival.

Mr Ivan Francis



As we celebrate 50 years of newborn screening in Victoria, we also celebrate and acknowledge the incredible contribution and commitment of Mr Ivan Francis to the program.

Ivan began working in the program in 1966. He has been instrumental in managing the laboratory, developing new tests and setting up the laboratory's databases and mentoring other scientists.

Ivan has also contributed to the development of newborn screening policy across Australasia and undertaken research looking at the impact of screening in the community.

This is a significant milestone and the program would like to take this opportunity to thank Ivan for his dedication to newborn screening and to offer our congratulations on such an achievement.



Our story

Meet Jack & Edward Baker

Our third baby, Edward, was born in October 2004. He was an active and loud nine and a half pounds! After our stay at St Vincent's Hospital, we took him home to meet his big brother and sister and all was well. A few days later however, we were called back for a repeated heel prick test as something needed to be checked.

Later, we received a call from The Royal Children's Hospital saying that they had results of the heel prick test and we had to bring Edward in for further testing as it looked like he had a 'serious and rare genetic condition'. The phone call left me with little information, confused and in tears.

We arrived at the hospital the next day and were met with a number of worried looking staff. We were told that Edward had a condition called Glutaric Acidemia (GA1) and that if untreated and unmanaged, he may suffer serious brain damage. We were devastated.

The team took charge and explained the possible health implications, and the management that was required. The doctors assured me that this condition could be managed with strict parental and medical guidance. It was certainly going to be a team effort.

Whilst absorbing the implications of what could happen to our second son, we realised that our first son may also have GA1. At age two, Jack began to show sudden unexplained physical symptoms. The doctors tested Jack.

continued over page

Image: Edward & Jack Baker

Sure enough, our next appointment with the team confirmed that we had two sons with GA1. We now knew that if a team of doctors enter the room, it's serious.

They explained that GA1 was included in the newborn screening (NBS) program from 2002, meaning Jack missed out on being tested at birth. If Jack had remained undiagnosed, he was at risk of significant brain injury. We were lucky.


Managing two boys with GA1 was very stressful. Some things were difficult, such as preventing fevers and medicating both boys. Hospital stays were traumatic as they involved invasive treatment, tears and sleeplessness. It was isolating and frightening. However, we got on with it and kept moving forward.

Now, 11 years later, our beautiful boys are happy and healthy. They suffer no lasting health impacts of GA1. They are doing well in sport and in school and continue to be kind and considerate.

The team of doctors and health professionals have helped us through the danger period and continue to manage their medical needs. It is always wonderful to catch up with the team at the boys' health check appointments and my heart fills with pride and relief when they tell us how well they are doing.

NBS helped protect my boys from serious brain injury and lifelong disability. I shudder to think what could have happened if we had refused the heel prick test. I am also very grateful to the metabolic team and the wonderful hospital team at The Royal Children's Hospital.

Leonie Baker



“Newborn
screening helped
protect my boys
from lifelong
disability.”

Our story Meet Ruby Kirwan

Ruby was born on a Monday evening and we were checked out of hospital and home on the Wednesday. It was still too early for newborn screening (NBS), which is recommended at 48 to 72 hours.

Our local maternal health nurse attended our home on the Thursday. We were having trouble with Ruby attaching to breastfeed, and this was the focus of her visit. She introduced us to NBS, and explained how it tested for several diseases. She returned on Friday to conduct the test, waited the recommended drying time, and posted the card on the Monday.

The following week we presented to the local emergency department with a very sick nine day old baby. As we were checking in at emergency, I took that unforgettable phone call. Ruby had returned a positive reading from the test, for a serious metabolic condition called Maple Syrup Urine Disease (MSUD). We needed to get her to The Royal Children's Hospital as soon as possible.

It was thanks to the NBS program that Ruby could receive the appropriate treatment in a timely manner to prevent any further brain trauma to what she had already sustained. As MSUD is one of the rarer conditions screened for, not many doctors have ever heard of it, let alone know how to treat it. I strongly believe if not for NBS she would be severely disabled, or possibly would have died.

We continue to rely on regular NBS monitoring to keep Ruby healthy today. We can monitor her protein levels and adjust her diet accordingly to keep her healthy.

Fiona Kirwan

Image: Ruby Kirwan



MAKING IT WORK

A state-wide team effort

Every day in Victoria, from Bairnsdale to Mildura, about 220 bouncing babies are born. Most are normal and healthy and soon go home with their parents.

A small percentage also appear perfectly normal at birth but are affected by a condition that could severely affect their development. Some of these conditions, such as phenylketonuria (PKU), are genetic.

Other conditions, such as hypothyroidism (in which the thyroid gland is absent or not functioning correctly), are not genetic but are caused by problems during development of the baby. These conditions can cause severe disability and even death if not recognised and treated quickly.

The good news is that newborn screening (NBS) is a simple test available to all Victorian babies that can detect many of these conditions, allowing treatment to commence as early as possible and minimising the long-term consequences of these conditions.

In the case of hypothyroidism the treatment is simple and highly effective: a small tablet containing thyroxine to replace the missing thyroid hormone, is taken daily. Some conditions, like PKU, require a special, lifelong diet.

The NBS testing process has been improved over the years and additional conditions have been added to the screening panel (see page 26). In 2015, babies are screened for 25 conditions.

While the test process sounds simple, making sure that all babies are offered screening requires dedicated effort from many health professionals.

For example, some babies are discharged early and require testing at home instead of in the nursery. Some are born premature or undergoing treatment such as transfusions. These babies require repeat samples at a later stage to make sure the testing is effective.

The laboratory results must also be cross-checked against the hospital records to make sure all babies are screened. The samples need to get to the laboratory promptly so that babies with abnormal test results can be followed up as quickly as possible.

All around Victoria, midwives, nurses, doctors, couriers and laboratory staff are working together to make sure that the system works as seamlessly as possible and as many babies as possible are tested. How well do we do this? Very well indeed. More than 99% of Victorian babies receive newborn screening.

A clearly abnormal result triggers an immediate referral to a specialist in Endocrinology, Respiratory or Metabolic medicine at The Royal Children’s Hospital or Monash Medical Centre.

The parents are then contacted to organise confirmatory testing and commencement of treatment.

Some babies will require regular monitoring of their treatment such as PKU babies who require regular measurement of their phenylalanine levels to ensure the dietary treatment is adequate.

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Disorder	Caused by	Problems if untreated	Treatment/management
Congenital hypothyroidism	thyroid gland unable to produce thyroid hormones (T3 & T4)	growth failure, intellectual impairment	thyroid hormone supplements
Cystic fibrosis	abnormal secretions in the body; in particular the lungs & pancreas	impaired digestive & respiratory function, infections & decreased lifespan	dietary supplements, physiotherapy
Amino acid disorders* - e.g. phenylketonuria (PKU)	defective enzymes that breakdown protein	developmental delay, intellectual impairment, seizures	dietary modifications, vitamin supplements
Fatty acid oxidation disorders*	defective enzymes that turn fat into energy	muscle problems, poor feeding, vomiting, seizures, sudden death	avoid prolonged fasting, dietary modifications

* These disorders affect the breakdown of fat & protein in the body.

Box 1: Conditions on the newborn screening panel



The newborn screening program is funded by the Victorian State Government and performed by Victorian Clinical Genetics Services, part of the Murdoch Childrens Research Institute (MCRI). The procedures and protocols used by the laboratory have been approved by the state government and are subject to regular audits.

The future NBS panel will undoubtedly change as technology advances and NBS for new disorders becomes feasible. Research at MCRI is helping to develop new tests for current disorders, as well as reliable and cost-effective tests for additional conditions.

The introduction of new NBS tests will also benefit from a national policy framework currently under development. The new framework will improve the way new tests are assessed for inclusion in NBS and will ensure the roll-out of any new tests is uniform across Australia.

Dr James Pitt



Our story Meet Sophie McAlicee

Our second daughter Sophie was born 10 days late by caesarean section. The first sign that I thought something might've been wrong with Sophie was around the second day after her birth when her stools were dark green.

We had newborn screening (NBS) performed on Sophie on day three and I honestly didn't think anything of it as our first daughter's screen was fine.

During the next few weeks at home, we noticed that Sophie wasn't thriving, was below her birth weight, didn't want to feed and had starting turning greyish in colour. Thankfully we had the district nurse come to visit us at home and she agreed that 'something' wasn't quite right.

During the fourth week she made an appointment for us to see the local paediatrician. He decided to do a series of tests, one of which was fat malabsorption in her stools. Whilst we were waiting for the results, we received a call from Lisette, a genetic counsellor from Victorian Clinical Genetics Services.

Lisette advised that she was calling about the heel prick test that had been performed on Sophie. She said that the tests had found one copy of the mutation for cystic fibrosis (CF). She asked me if I knew what CF was and I explained that I knew two young girls with the condition.

I was aware that it affected the lungs and that life expectancy was around 20 years, but not much else.

Lisette advised that for someone to have CF they needed to inherit one gene from each parent, and that if both parents carried the gene, a child has a one in four chance of having the condition.

After hanging up the phone from Lisette I felt absolutely devastated and heart broken. I rang my husband and broke the news and we drove the six hours to Melbourne that afternoon for further testing. That trip to Melbourne was one of the longest, most emotional trips I have ever taken and to this day will never forget it.

The next few days were a blur with testing, medical and dietitian appointments, physiotherapy and counselling. Life as we knew it had changed forever. Our days were filled with learning how to give enzymes to a baby to help with absorption of fat, how to do physio and percussion and receiving education about the diet of a person with CF.



Sophie is now 10 years old and thriving. She is starting Grade six next year and has been appointed part of the leadership team at school and was also voted as the leader of the Junior School Council. She excels at hockey (which she learnt whilst in hospital doing physio), netball and blows me away when public speaking.

She lives life to the fullest and does not let CF take over her life. She is also a wonderful teacher to her younger brother Gabriel, who also has CF. She has taught him how to swallow tablets and breathing techniques for physio and generally looks out for him.

I am so thankful for the NBS program. Sophie was diagnosed early and treatment could be started straight away. If Sophie had been born prior to 1989, when the gene for CF was first found, she may have had a lesser quality of life.

Carolyn McAliece

Image: Sophie McAliece

COLLECTING THE SAMPLE

Role of the midwife

I currently work as a midwife in private practice, and have done so for the past six years. I work in a ‘continuity of care’ model, meaning women attend our clinic to be able to see the same midwife throughout pregnancy, birth and the postnatal period. Through this time we build a relationship of respect and trust.

Our clinic, Midwives and Mothers Australia (MAMA), focuses on nurturing and supporting the woman and family, and naturally this extends to taking blood tests.

As a midwife part of my role is to discuss, obtain informed consent for and conduct various blood tests throughout the pregnancy and the postnatal period. **The newborn screening (NBS) test is the only routine blood test recommended for babies in Victoria, and it is one I highly encourage all my clients do.**

When I learnt how to do the NBS test, I learnt from a midwife in the hospital who believed it was best to take the baby away from the mother to do the test, to avoid her getting distressed. I found this experience more distressing for both the newborn and myself, as the baby had no mechanism for comfort, became upset and inevitably, the samples were harder to collect.

It was not until another midwife showed me how to ‘prepare’ the baby for this test that I became completely comfortable with it. Since then, I have not done the test any other way.

Firstly, I always ensure the baby’s foot is warmed, either in the parent’s hands or with clothing. Then after explaining the test to the parents, I advise how colostrum and sucking gives the baby endorphins which reduces the pain. I have not had a client decline to do the test this way since, and often the baby will not even cry when it is done this way. It’s a better experience for both mum and baby.

Kelly Langford, MAMA

Image (L to R): Angelo, Robyn, baby Orlando, Jan





TEST PROCESS

& statistics

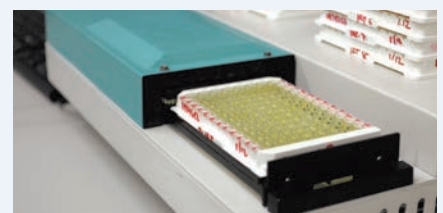
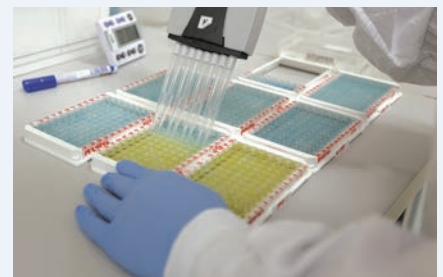
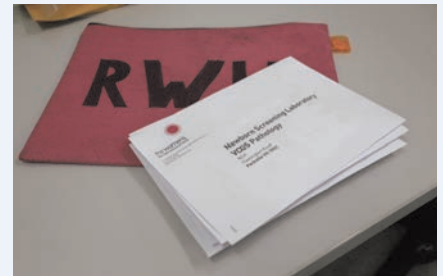
1. Ideally, parents are informed about newborn screening during antenatal care. A brochure is provided that explains the tests.
2. Between 48 to 72 hours after birth, a midwife will obtain written consent to perform the test.
3. A few drops of blood are collected via a heel prick and soaked onto a special absorbant card, which is then air dried.
4. Cards are couriered or express posted to the Newborn Screening Laboratory, Victorian Clinical Genetics Services at The Royal Children's Hospital in Melbourne.
5. A small punch of the blood spot is removed for three types of tests:
 - thyroid stimulating hormone (hypothyroidism);
 - immunoreactive trypsinogen (for cystic fibrosis);
 - amino acids and acyl carnitines (for phenylketonuria and other metabolic conditions).

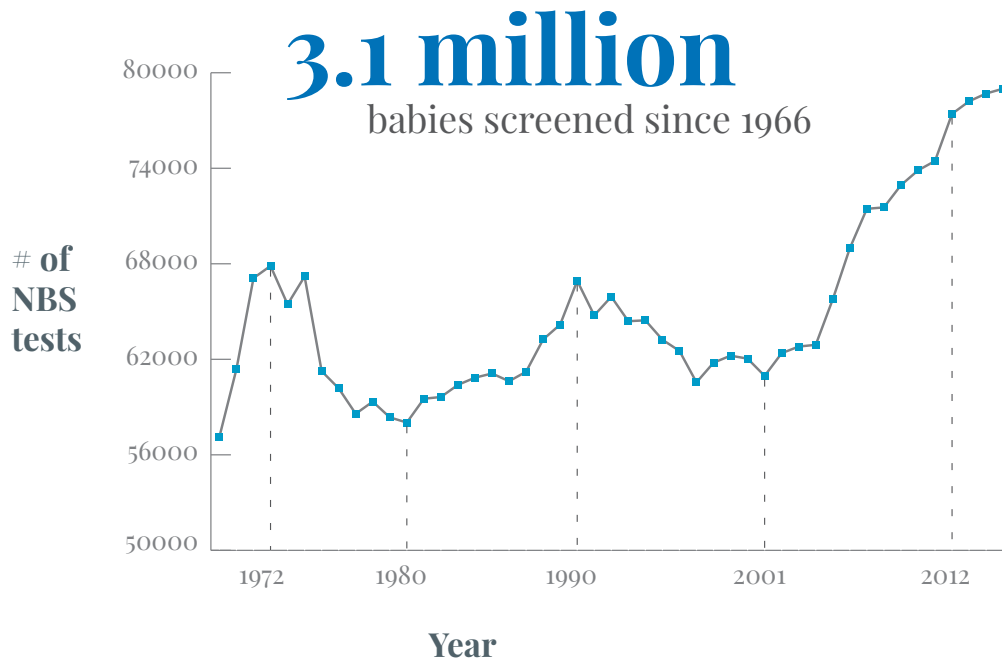
\$20

cost of NBS
test per baby

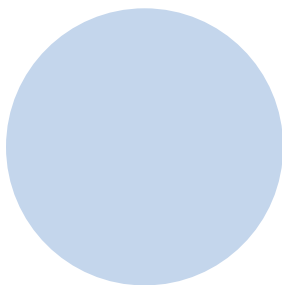
99%

of Victorian
babies undergo
screening

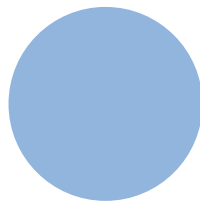




In 1 year...



35 cases
hypothyroidism



24 cases
cystic fibrosis



11 inborn errors
of metabolism



7 cases
phenylketonuria



NEWBORN SCREENING

Thanks & credits

The newborn screening team would like to thank:

- the Victorian State Government, for their ongoing financial support of this vital public health program;
- the Karlecik, the Turner/Fourie, the Baker, the Kirwan & the McAliece families for their contributions to this book;
- Kelly Langford from Midwives and Mothers Australia for her contribution to this book;
- all the midwives, nurses and other health professionals across the state who do a fantastic job on the ground, collecting samples and working with parents;
- the clinical specialists & laboratory staff associated with the newborn screening program;
- Victorian Clinical Genetics Services and Murdoch Childrens Research Institute for their ongoing support;
- Mr Ivan Francis, for his longstanding commitment to the program over the last 50 years.

In addition, special thanks to Sally Morrissy and Taryn Charles for their efforts in compiling this celebratory book.

We look forward to the next 50 years of healthy babies.

Image: Newborn Screening Laboratory Team

Back L-R: Nick Tzanakos, James Pitt, Joe Karlecik

*Front L-R: Sally Morrissy, Thanh Nguyen, Maggie Tan, Lan Trieu, Doris Wong,
(Absent: Sheila Theresa).*

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Layout and design: Taryn Charles, 2016



