

CYN^et



Health of our children: Wealth of our nation

Newsletter of the Advisory Group for New Zealand Child and Youth Clinical Networks

Issue 1 - 2016



From the Chair

Welcome to the 5th edition of the NZ Child and Youth Clinical Networks newsletter. Our network program continues to expand and includes important work across a wide range of areas in child health. I congratulate the members of each network for achieving so much over such a short period of time.

In this newsletter we welcome a new member of the Clinical Advisory Group, Mary Roberts. Mary brings extensive expertise and experience to the group as outlined in her brief CV included below. We are delighted to have her contributing to the program.

This newsletter is somewhat larger than previous editions, which reflects the scope of work underway. I hope that you will find time to read these informative updates from our Allergy, Palliative Care, Diabetes and Cardiac Inherited Disease Networks and the Child and Youth Epidemiology Service.

We welcome feedback on the content of this newsletter and ideas for future content, please see the contact details for Lauren Young at the bottom of the final page.

Richard Aickin

Chair, New Zealand Child and Youth Clinical Network
Advisory Group

Clinical Network websites

For more information on what is happening with the 11 NZ (national) Clinical Networks check out the front page below or go directly to the specialist CN

www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks/

www.starship.org.nz/diabetesnetwork/

www.starship.org.nz/gastroenterologynetwork/

www.starship.org.nz/newbornnetwork/

www.starship.org.nz/childprotectnetwork/

www.starship.org.nz/palliativecarenetwork/

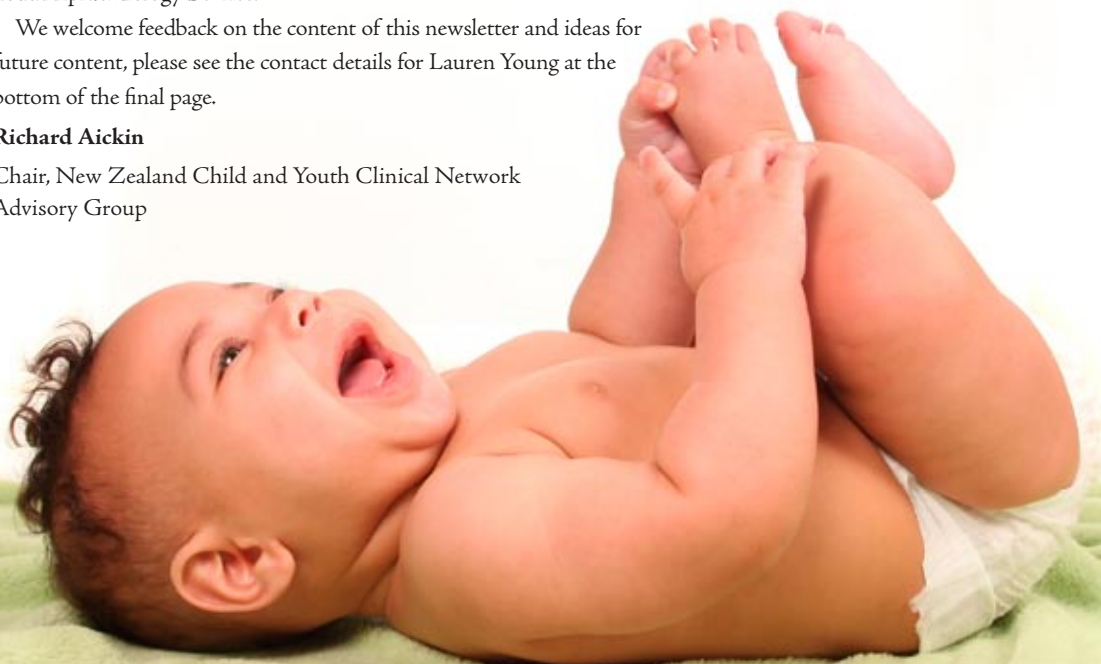
www.starship.org.nz/cysticfibrosisnetwork/

www.starship.org.nz/sleepnetwork/

www.starship.org.nz/tubefeedingnetwork/

www.starship.org.nz/eczemanetwork/

The Paediatric Allergy and Neurology web sites are under development and will be live in a few weeks.



The Paediatric Society of NZ looks to the future

Dr Russell Wills, NZ Children's Commissioner and Community and General Paediatrician addressed the PSNZ Council meeting in Auckland on 8th April. His talk was focussed on key issues he and his team from the Office of the Children's Commissioner had identified for New Zealand tamariki – children. This presentation was to inform the development of PSNZ's strategic focus for the next 5 years to 2021 and beyond.

Dr Wills began with a national environmental scan, showing that around 25% of our children are now living in poverty which has increased from 15% over the last 3 decades. He highlighted the evidence that Pasifika and Maori children grow up more often than other Kiwi children in conditions of poverty and disadvantage which is associated with their much higher rates of hospital admissions for conditions ranging from skin infections, asthma and acute rheumatic fever to assault and neglect. Russell also pointed out the financial costs of referrals to and involvement of CYFS, Work and Income and Corrections. Clearly, we as the Paediatric Society of New Zealand have a role in reducing the inequities suffered by our children and in the negative outcomes that this inequity promotes.

Russell reminded us of our vision statement, *"All children and youth by right should obtain optimal physical, mental and social health and wellbeing and by working as a coordinated national network of health professionals dedicates its efforts and resources to this end."*

So, where will we be in 2021? The PSNZ Council has committed to working toward the Society being:

- Connected, multi-disciplinary, diverse, and responsive
- The go-to body for child-health - sought for advice, a voice for children and young people, politically connected but independent and focussed on the needs of New Zealand's tamariki - children
- Working towards an increased primary care focus

To achieve these goals we will:

- **Grow** our society to increase our capacity to be effective professionally and personally
- **Connect** with each other, our colleagues in related sectors and government and non-government agencies via tools such as our SIGS, Clinical Networks, Listserv and Annual Scientific Meeting
- **Improve practice** - through Clinical Networks, SIGS, educational support and facilitating discussion opportunities and fora
- **Advocate** for children



Children's Commissioner Dr Russell Wills

Each of these actions needs measurable objectives, a plan and resources of people and funds.

Russell reiterated that we have many strengths as an organisation, such as a membership of over 500 experienced, dedicated and talented people throughout the country, Clinical Networks, relationships with each other and the Ministry of Health.

We will need to effectively overcome our 'busyness' in order to improve our capability to address gaps, raise our public profile and extend our advocacy for our children, young people and families. Our opportunities include the review of CYFS, the new MoH strategy which includes sharing innovation and IT and our links with organisations with common goals such as Ko Awatea, OCC, CYFS and primary care organisations. Our threats include pressures on our budgets and our time plus a political focus on obesity.

The diagram below suggests where we should direct our efforts.

Thank you Russell for your presentation and for your dedication and work on behalf of the children of Aotearoa. The clarity of thought and the intensity of focus that you brought to our strategic process will enable us to more effectively direct our energies going forward. We wish you well as you move on to other challenges from your powerful advocacy as Children's Commissioner. We are committed to ensuring that all Kiwi children and young people have the opportunity to grow up healthy, safe and participating in a fair society where material hardship is not permitted to constrain their or our futures.

David Newman, President PSNZ



Paediatric Allergy National Clinical Network

Food allergies get new focus

Atopic diseases have increased in prevalence in recent decades. In particular food allergy has become an increasingly common problem affecting children and young people. Historically there has been a lack in training relating to allergy leading to a lack of expertise. In 2006 a Special Interest Group (SIG) for Paediatric Allergy was formed with the purpose of providing collegial support for paediatricians around NZ developing services to meet the needs of allergic children. A significant focus for the SIG has been food allergy, with development of resources on an ad hoc basis, predominantly used by SIG members.

In becoming a Network under the Paediatric Network programme we aim to develop more defined pathways for assessment and management of these patients on a national basis incorporating aspects of primary, secondary and tertiary care. The network will develop, promote and share clinical guidelines relevant to primary, secondary and tertiary care of allergy patients with a mechanism to disseminate. It will be a forum to discuss and resolve issues. Standardised guidelines should result in better patient care and clinical outcomes.

The focus of the Network initially will be to undertake a stock take across primary, secondary and allied health services of availability of allergy investigation and treatment. Initial guidelines will address allergy testing, venom allergy and drug allergy.

Ultimately we hope the Network will result in:

- Consistency of care around New Zealand.
- Improved linkages between families, primary, secondary, tertiary care and allied health.



- Clear guidelines and resources to support diagnosis and management in primary and secondary care, plus to support families and young people with issues of self management of in particular food allergy.
- A central voice to liaise between health and education over issues relating to managing risk for food allergic children and young people in education settings.

Key Performance Indicators	
KPI	Measure
Develop guidelines and resources, and promote existing resources to support allergy care	Develop guidelines, to be available on web <ul style="list-style-type: none"> • Allergy testing • Venom allergy • Drug allergy Web site hits Use of ASCIA e learning modules (anaphylaxis, food allergy)
Assess equitable access to care	Survey DHB <ul style="list-style-type: none"> • Access to allergy testing • Access to food challenge Hypoallergenic formula prescription by region as surrogate marker
Workforce development	Provide training and education <ul style="list-style-type: none"> • Primary care including Tamariki Ora providers • Medical school and specialist training

International conference on Paediatrics and End of Life Care

On April 11 2016 an international programme that provided 'Education in Paediatric and End of Life Care (EPEC *)' was held at Auckland District Health Board' education centre. The EPEC is a unique, internationally recognised programme, to educate senior health care professionals (paediatricians, nurse practitioners and others in advanced practice) in the essential clinical competencies of palliative care.

The overall aim of the Train the Trainer conference was to provide a practical and evidence-based approach as to how to teach paediatric palliative care. We had 54 attendees from NZ, Australia, Southeast Asia and UK along with 4 senior master facilitators from the USA, we had 3 other master facilitators – one from Australia, India and Karyn Bycroft from Starship who organised the conference.

Participants were given skills to teach others in their respective local hospitals and organisations. A major benefit of the programme is improved care for children and their families with palliative care needs. Other benefits include the ability to disseminate consistent up-to-date information to the wider community involved in providing paediatric palliative care.

Paediatric palliative care involves a wide range of skills and teaching this range of skills requires differing approaches. For example, teaching knowledge and skills versus teaching how to change attitudes and behaviours requires flexibility. With each

Train the Trainer

ADHB 11 April 2016

session there was a focus on the core principles of teaching: hook, teaching knowledge, addressing attitudes and teaching a skill. This was demonstrated in small workshops and incorporated, direct teaching, discussions, role plays with some humour as well.

Topics presented at the conference included: Teaching pain and symptom management; Teaching with EPEC – Paediatrics in the face-to-face setting; Team collaboration and effectiveness; Self-care for professionals; Communicating and planning; Quality improvement implementation.

The participants also have a requirement to complete 18 on-line modules in addition to the conference. Overall the feedback has been extremely positive from all involved – those with many years of specialist experience to those just beginning in this field of care. All stated how worthwhile the conference was and how the practical skills will assist them to provide excellent palliative care to children and families.

The organiser of the NZ based programme was Karyn Bycroft, a Nurse Practitioner at Starship Childrens Health, Auckland and a member of the national Paediatric Palliative Care Clinical Network.

This conference would not have been possible without the financial support of the Starship Foundation, Christchurch Children's Haematology & Oncology Centre and the Rotary Club of Ellerslie Sunrise.



Left to right: Mary Ann Muckaden – Professor and Head Palliative Medicine, Tata Memorial Centre, Mumbai. Stacy Remke, MSW, LICSW, University of Minnesota and Stefan J. Friedrichsdorf, Medical Director, Department of Pain Medicine, Palliative Care & Integrative Medicine, Children's Hospitals and Clinics of Minnesota, Associate Professor of Pediatrics, University of Minnesota

At school with diabetes

Schools are bound by a “duty of care” to provide a safe environment for children. The extra challenge is when a child has a chronic healthcare issue such as diabetes mellitus. Schools need to prevent risks from injury and ensure that children with health issues are given the same opportunities at school as all other children. However, diabetes mellitus in childhood is a complex condition that can potentially make school life complicated and stressful.

The National Diabetes Schools Project was a collaborative project involving the Paediatric Society of New Zealand (PSNZ) National Child and Youth Clinical Diabetes Network, consumer representatives from Diabetes Youth New Zealand and a National Working Group of interested and experienced Paediatric and adolescent medical and allied health professionals. Expressions of interest for membership on the working group were invited in November 2014. The project aims were to

- identify current care practices and available diabetes educational resources being used within schools
- establish consistency in National standards in Paediatric diabetes care in schools,
- develop a National Diabetes in Schools Tool Kit.

Phase I Needs Analysis

In early 2015 Diabetes Youth NZ in collaboration with the National Schools Project working group, designed and coordinated a national electronic survey to collect information regarding the availability of diabetes specific resources for schools and to identify areas of need. The total sample size (n=408) comprised parents and care givers (n=239); school nurses and school personnel (n=129) and nurses involved in the care of school children but not based within schools (n=40). The survey revealed significant findings in three main areas; the provision of care plans, availability and access to specialist education and support, and knowledge levels in relation to the process of NZQA special assessment consideration for medical reasons.

School Healthcare Plans

The Ministry of Health (2006) clearly outlines the need within schools for robust health policies and further recommends that all children who meet the following criteria need a Health Care Plan at school

- their condition could be life-threatening
- their condition could require hospitalisation
- regular medication needs to be administered
- regular monitoring is needed
- their learning environment needs regular control/adaptation
- their activities need to be managed or restricted
- they have to be absent from an ECE service or school regularly because of their health condition

The survey reported that most children with diabetes had a health care plan at school (approximately 60-80% across the 3 streams) however one third of school personnel and half of the nurses could not identify how often the care plan was or should have been updated. School health care plans for children with diabetes must be updated annually in collaboration with families to reflect any changes in diabetes therapy regimes and to address developmental change in levels of independence. 30% of consumers



Jordan about to administer insulin at school.

reported that they had not had any involvement in the development of the school health care plan for their child.

Provision and access to Specialist diabetes education and support

School personnel must receive adequate training by specialised healthcare personnel to provide or supervise care of children with diabetes. The provision of specialist diabetes education and training was reported by 60% of the nurses. Two thirds of the school respondents and 70% of consumers had been provided with additional educational resource material. Of significant concern were 40% of the nurses reporting a lack of confidence in administering an intramuscular injection of glucagon for severe hypoglycaemia. Almost 90% of consumers; around 70% school staff and 85% nurses wanted access to more educational resources and supported the development of a video resource and New Zealand specific care plan that could be used at a national level.

High Health Needs Funding (HHNF)

The Ministry of Education (2016) provides clear eligibility criteria around the provision of HHNF. In general, otherwise well children with diabetes mellitus being treated on insulin therapy do not strictly meet HHNF criteria (with the exception of high risk developmental periods such as transition from pre-school to school or post commencement of insulin pump therapy). Children with diabetes mellitus requiring insulin therapy and co-existing co-morbidities affecting their ability to meet developmental

milestones (for example autism, trisomy 21, developmental delay, mental health concerns) will generally meet criteria for HHNF although regular assessment of their developmental abilities should guide renewal applications. The provision of high health needs funding reported within the survey was relatively low with 29% of consumers reporting the use of a teacher's aide (1.5-16hrs/week). Similarly 35% of schools reported allocating HHNF (variable hours) for children with diabetes (data regarding the presence of comorbidities was not collected and it is possible that some children with an allocation of high health needs funding were eligible on the grounds of health care issues other than diabetes alone).

NZQA and Special Assessment Conditions

NZQA grants entitlement to Special Assessment Conditions (SAC) so that approved candidates may be fairly assessed and have access to assessment for National Qualifications. Children with diabetes mellitus requiring insulin therapy are eligible for SAC. Applications are made by schools on behalf of candidates. In the majority of cases schools will require as additional documentation to the SAC application, a certificate/medical report from a registered medical specialist attesting to the presence of diabetes with details around the reasons for entitlement to special assessment consideration. Only half of the consumer group were aware of SAC related to their child's diabetes and 35% of nurses did not have any knowledge around the required process for SAC.

The survey highlighted significant educational gaps with a focus on the need for educational resources to support consistent standards of care to ensure that children and young people with diabetes across New Zealand have the same opportunities at school as their peers.

Phase II Review and benchmarking of current available resources

Between January to March 2015, the National Schools Project working group undertook a comprehensive review of available resources being used within NZ in the following areas; Auckland, Waikato, Wellington, Christchurch and Hawkes Bay. A further review of resources being used within Australia (Royal Children's Hospital and Monash Medical Centre in Melbourne, Princess Margaret Hospital, Perth, The New Children's Hospital, Westmead) was also undertaken and the Diabetes UK collection of school resources also reviewed. Significant variability in approach to school based management of hypoglycaemia, blood glucose target ranges and exercise was evident within New Zealand. And, there were also slight differences in management approaches between New Zealand and Australia and the UK. The collection of resources were benchmarked against international clinical consensus guidelines (ISPAD, 2014; APEG, 2011; ADA 2015) and it became clear that slight differences in interpretation of the guidelines, specifically in relation to school based hypoglycaemia and ketone management had evolved into differences in practice over time.

Phase III Trans-Tasman Collaboration

In the course of reviewing the Australian collection of resources, the Clinical Network discovered the Diabetes Australia School Action and Management plans, which aligned most closely with practice in New Zealand. These plans are the original work of collaboration between Diabetes Victoria, The Royal Children's Hospital and Monash Children's Hospital, Melbourne, Australia. In April 2015, the PSNZ Diabetes Clinical Network and Diabetes Australia Victoria entered into a formal collaborative professional agreement to adapt the Australian plans for use in New Zealand. The process of review and development of the New Zealand adaptations for primary and intermediate schools occurred over a six month period from April to October 2015. It is important to note that there are significant differences in approach to hypoglycaemia and ketone

testing between the Australian and New Zealand versions.

The NZ plans were published to the PSNZ Clinical Network website with active hyperlinks from the Kidshealth, New Zealand Society for the Study of Diabetes (NZSSD), the Aotearoa College of Diabetes Nurses (ACDN) and Diabetes Youth New Zealand (DYNZ) websites in November 2015. Second phase NZ adapted versions of the action and management plans for pre-school and early childhood settings were developed between late 2015 and March 2016. These were published to the Clinical Network website alongside the primary and intermediate school plans in April 2016.

All the plans are provided for use in secure PDF format only. They need to be printed and individualised by hand (filling in name and other details, ticking relevant boxes where indicated) by the diabetes treating team in consultation with the child/young person and their family (for children under 13 years), or by the young person in consultation with their family and relevant school health personnel (i.e. school nurse, health care assistant/first aid officer) for those at intermediate or college level school. There are three sets of plans that address care requirements for the three main types of insulin regimens used within Paediatric and adolescent diabetes. The action plan is a one page document that is designed as a quick guide to summarise generic aspects of care for diabetes at school and act as an identifying medical document. The accompanying management plan is a much longer document designed to capture specific individualised information regarding each child's care. Each year, families are encouraged to initiate with their healthcare team a review of the plans to reflect any developmental changes in care requirements.

The National Roll-Out

The National roll-out of the school plans was via electronic networking (email and website promotion) between November 2015 to April 2016, to the Paediatric Society of New Zealand, ACDN, NZSSD, New Zealand College of Primary Care Nurses, and direct to consumers via DYNZ. A journal article was provided at the request of "Logic", the official Journal of the Primary Health Care Nurses, New Zealand in early 2016. Within Auckland, the release of the documents was promoted via the Auckland School nurses and Auckland Primary Health Care nurses electronic networks. All 500 children within the Starship Diabetes Service attending clinics between January to April 2016 were provided with individualised plans developed collaboratively as part of the clinic consultation. National DYNZ Newly diagnosed packs were updated with the new plans from January 2016. A publication was also requested by Diabetes Youth Auckland for their quarterly consumer newsletter, "Youth Buzz".

The National Schools Project was shared via oral presentation at the NZSSD Annual Scientific Meeting Paediatric Diabetes Study Day in May 2016, and a further presentation by the Diabetes Australia Victoria group regarding the Diabetes Australia Victoria School plans roll out in Australia and the more recent Trans-Tasman collaboration with the PSNZ Clinical Network, is planned at the Australasian Paediatric Endocrine Group (APEG) Annual Scientific Meeting in November, 2016 as part of a forum regarding standards of diabetes care within schools.

Stage IV Interactive Resources and Development of a Position Statement

The third and final phase of the National Diabetes Project will see the Starship Children's Health Paediatric and Adolescent Diabetes service complete the development of an online educational module for school personnel. It is anticipated this online module will become available by mid-2016 via the Starship website and will be promoted to all schools via the Auckland Schools electronic network. Ongoing liaison with

Continued on final page.

Looking for that all important data on



the health of children and young people?

The latest set of reports from the New Zealand Child and Youth Epidemiology Service (NZCYES), “The Health Status of Children and Young People” is being printed and will be with the DHBs shortly.

Each year the New Zealand Child and Youth Epidemiology Service (NZCYES) of the University of Otago offers the New Zealand health sector up-to-date information on the health of children and young people. Its reports provide an evidence base for policy development in child and youth health for district health boards and the Ministry of Health. They highlight areas where there are disparities in child and youth health or where inequities in service provision mean that children and young people are not reaching their full potential.



NZCYES staff at the recent workshop run for the DHBs and Ministry of Health: Dr Judith Adams, Glenda Oben, Dr Mavis Duncanson, Sarah Gallagher, Dr Jean Simpson, and Andrew Wicken

Contracted by the DHBs and the Ministry of Health, these reports contain analyses of national level data, including data specifically for Māori, and for Pacific children and young people, and customised analyses for each DHB population. Produced in hard copy and electronically for the MOH and DHBs, the reports have graphs and tables related to the indicators described and reviews of the recently published evidence related to these indicators. Two in-depth reviews of topics of interest in child and young people’s health in New Zealand are included each year. Our website (www.otago.ac.nz/nzcyes) has copies of these reports and reviews and lists the indicators and topics covered by these reports since 2007.

The NZCYES team also runs an annual two day conference/workshop. This workshop provides a valuable forum for staff from the DHBs and Ministry of Health who are involved with children’s and young people’s services to hear about emerging research and current practice, and importantly, to network. About 100 people attended the most recent workshop held at Te Papa in Wellington in the last week of May.

In addition, the NZCYES visits each DHB annually to discuss the most recent report. If you have not been aware of these meetings, we’d love to see you and in particular hear your views on how best we can help with your information needs. Please check with your Clinical Director, Child Health and Portfolio Managers as to when the NZCYES team will be at your DHB.

Dr Jean Simpson

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The Cardiac Inherited Disease Registry and Clinical Network

What is this?

Known as CIDG (the Cardiac Inherited Disease Group), this is a national network of clinicians, allied professionals and scientists whose core aim is the reduction of sudden death in young people due to inherited heart conditions. CIDG aims to **DETECT**, **PROTECT** and **ENABLE**. **Detect** those at risk of sudden death, **protect** them, and **enable** them to return to as normal and active a life as possible. Of course we also seek to reassure those who are not at risk, and save them from unnecessary prolonged clinical follow up.

How does it work?

CIDG runs a national registry of cardiac inherited diseases (CID), which includes not only conditions like long QT syndrome and hypertrophic cardiomyopathy, but also sudden unexplained deaths and resuscitated cardiac arrests in children and young people. The registry is consent-based and has had national ethical approval since 2009. A full list of the conditions we currently register is shown in table 1 with approximate current numbers of individuals currently registered.

The registry operates with a hub and spoke model, with the main hub being in Auckland, with the national coordinator being Jackie Crawford, one of the founder members, and a cardiac physiologist by profession (pacemaker/defibrillator technologist). She receives and coordinates referrals from Auckland north and the whole of the south island. Mandy Graham is a cardiology nurse and coordinates the Midland regional registry, and Tom Donoghue, also a cardiology nurse is coordinator for Capital Coast and the Central Region. Thus there are three hubs, each with its own coordinator, cardiac genetic team and clinical leader. A new hub is shortly to start in Christchurch for the south island; it is hope the new coordinator will be appointed later this year.

The regional hubs link to the district hospitals, most of which are represented formally in CIDG. A full list of the teams can be found on the website (www.cidg.org.nz).

Why have a national registry?

Most CIDs have autosomal dominant inheritance. Thus 50% of first degree relatives will carry any at risk gene. The most effective way to identify at risk individuals in the community is through effective family cascade screening combining cardiac

tests such as ECGs and echocardiography, with genetic tests. Families are spread across New Zealand, and the world, it makes no sense to have fragmented services. Genetic tests should not be done in isolation from cardiac phenotyping, since so many of these conditions have variable penetrance, and many of the genetic mutations are unique, with uncertain levels of pathogenicity.

90-100 sudden cardiac deaths occur each year in New Zealand in 1-40 year olds. Most of these are reviewed by CIDG. Review of such cases is a powerful driver to try to prevent them. Sudden death in inherited heart conditions is preventable.

How does the national cardiac inherited disease registry work?

A referral of anyone with or suspected of a cardiac inherited condition can come from anyone to the coordinator- GP, paediatrician, cardiologist, pathologist, allied professionals and lay public. Simply send an email or make a phone call. All can be reached by the central administrator cidgadmin@adhb.govt.nz. See figure 1. The appropriate coordinator is notified and he or she will gather information about the case and refer to their team and arrange appropriate clinical follow up. Usually this means some cardiac tests, and considering genetic tests, and facilitating effective family screening, which is done in dedicated combined cardiac genetic clinics

The national clinical leader is Jon Skinner, Paediatric cardiologist/electrophysiologist at the Starship. He has a multidisciplinary team in Auckland which meets fortnightly, coordinated by a team admin support, a clinical coordinators, two adult cardiologists, (Warren Smith, Andrew Martin), Clinical geneticist (Ian Hayes), Molecular geneticist (Don Love) and Forensic pathologist (Joanna Glengarry), and one or two genetic counsellors. The regional coordinators beam in by videoconference. New cases and new results are presented and manage plans outlined. Similarly, due to a formal national relationship with the national forensic service, new sudden deaths are reviewed in detail, and decisions are made about the value of genetic testing and family investigations.

Who pays for genetic tests?

Genetic testing following a sudden death (the so called "molecular autopsy") is funded by a national budget from

Prevent sudden death in the young

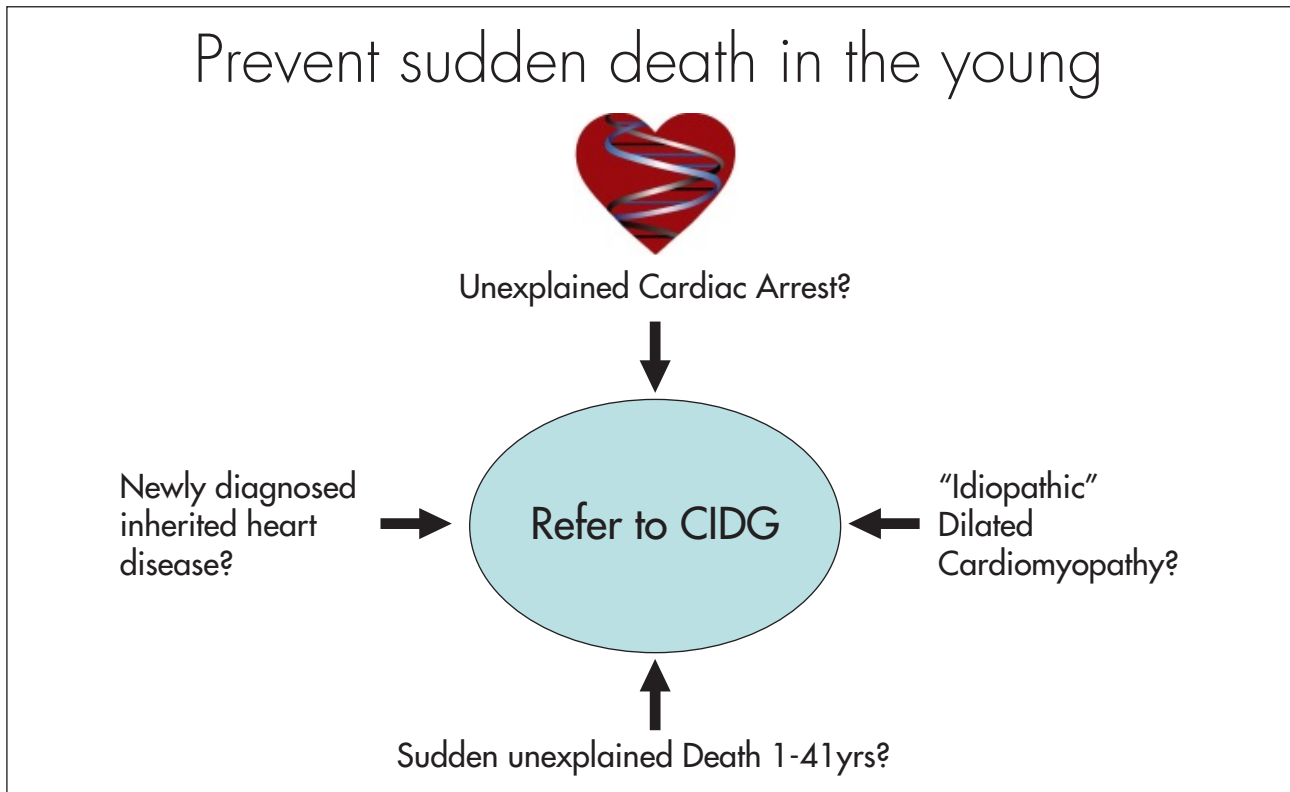


Figure 1 The main message: a simple one for doctors! Thinking of a cardiac Inherited Disease? Refer to CIDG.

the Ministry of Justice, held at Lab Plus in Auckland, and administered by CIDG. Any case from any region can be tested with these funds through CIDG.

Genetic testing in live individuals varies from region to region, some are funded through the clinical genetic service, and some via the paediatric, paediatric cardiology, or cardiology departments.

Who orders the genetic tests?

These tests can only be ordered by clinical geneticist or genetics associates and a small group of cardiologists accredited through working within the CIDG framework.

How successful has the program been?

There are many points of success. Auckland has the highest rate of detection of long QT syndrome in the world.¹ The molecular autopsy program, combined with cardiac testing of family members, routinely identifies an inherited heart condition as a cause of death in about one third of cases when no cause was found at autopsy.² Over 2,200 individuals from families with Cardiac Inherited Disease are registered nationally. Families appreciate being in a registry and get a sense of protection from it. Families of sudden death victims are particularly appreciative of what CIDG does for them. Families and clinicians are notified of important new discoveries indicating a change in management, and there have been many successful research and clinical reports from New Zealand (more than 50),³⁻⁷ including genetic discoveries.^{8,9}

The main point of weakness is the poor referral rate of the south island, despite the general willingness and enthusiasm of many relevant clinicians. This will no doubt improve with a locally based coordinator. The first two combined cardiac genetic clinics have recently been held in Christchurch.

Should paediatricians and paediatric nurses and other allied professionals be part of this program?

Yes. A number already are, such as Fraser Maxwell in Hamilton, Alex Binfield in Christchurch, Jeremy Armishaw in Tauranga, Nicky Webster in Palmerston North, Stephen Butler in Taranaki. We all meet nationally by video conference every two months, new cases, management issues and educational reviews form the focus. New members are welcome, including trainees. We have many potential exciting research projects waiting to be done from the bench to the community. Anyone needing a PhD, come and see us!

Table 1 Numbers of families and individuals registered with the CIDG national registry, May 2016.

Condition	No of families/probands	No of individuals registered with CIDG	Gene positives
Long QT syndrome	377	903	516
Brugada Syndrome	57	60	19
CPVT*	20	39	8
PCCD#	5	10	1
Dilated Cardiomyopathy	64	137	16
Hypertrophic cardiomyopathy	403	529	154

*CPVT: Catecholaminergic polymorphic ventricular tachycardia. # PCCD- Progressive Cardiac Conduction Disease. In addition we have currently 62 individuals with a sudden unexplained cardiac arrest. 481 sudden deaths over 1 year of age have been processed by CIDG.

How can you find out about it?

Take a look at the facebook page (Cardiac Inherited Disease Group) and the website, www.cidg.org.nz. You will find useful information about inherited heart conditions, referral forms, and news items. We want representatives in each region and at each hospital and welcome new ideas.

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At school with diabetes, continued.

Diabetes Australia Victoria regarding further collaboration on the development of a New Zealand version of the Diabetes Australia Victoria, "Mastering Diabetes Pack" for school personnel is also underway. It is anticipated that this will incorporate a National consensus statement regarding the management of childhood diabetes within school settings within NZ. A preliminary discussion with Diabetes Australia Victoria regarding the possible development of plans related to the management of Type 2 diabetes in schools has been initiated. A request for a National template to be developed for NZQA SAC to sit alongside the schools plans has been lodged and the Clinical Network is in the process of adapting the current template used by the Starship Paediatric Endocrinology department for National release by mid-2016. Diabetes Youth New Zealand continues to work in close collaboration with the Clinical Network in exploring the possible development of a video-resource for school personnel and families to complete the National Schools Tool Kit.

The provision of consistent standards of school based healthcare is central to improving the lives of children and youth with diabetes, removing inequalities and supporting the right to a good education. Health care professionals have a pivotal part to play in the promotion of safe environments for children and young people with diabetes at school, and can make a significant difference to how the future of healthcare within schools in New Zealand is managed.

The Clinical Network would like to thank Karen Crawford, and Renae Roll, Credentialed Diabetes Educators, Diabetes Australia Victoria for their tireless

Contact Jon Skinner if you wish (jskinner@adhb.govt.nz) or one of your local colleagues or coordinators.

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support in this collaborative venture. The Network would also like to thank the following members of the National Working Group; Neil Owens, Vickie Corbett, Kirsty Newton, Grace Harris, Rita Sigley, Gilli Lewis, Eve Natusch, Tina Cook, Jan Thompson, and Dr Wendy Hunter. A special thank you goes to Renata Porter, past president of DYNZ and overall coordinator of the National Schools Survey and Dr Jinny Willis for her support with data analysis.

New Advisory Group member

Mary Roberts is currently the Clinical Manager for TAHA Well Pacific Mother and Infant Service, based with the Pacific Health team, University of Auckland. Mary is a Registered Nurse who specialises in child health. Having worked in Primary Healthcare for many years, she has worked for Plunket, South Seas Healthcare, Mangere Family Doctors, Bader Drive Healthcare and at Alliance Health + Primary Health Care Organisation as the Nurse Educator. She has a Bachelor of Health Science (Nursing), Postgraduate Diploma in Health Science and has also achieved her Masters of Nursing. Married to Michael, and mother to four children: Hereine, Michaela, Joseph and Sasha.



New national clinical network resources and information are frequently being loaded on to the web site. Check out www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks to see if your speciality interest has new information.

Your contributions We welcome thoughts, contributions and articles and notices of upcoming events. We anticipate publishing updates around every six months. Please email the editor, Lauren Young on lauren@laurenyoung.co.nz