

21 September 2021



Official information request W21-649

I refer to your official information request sent to our Communications team dated 31 August, and received in this office 02 September 2021.

Request and Response:

1. How many surgical procedures have been carried out each year in relation to hypospadias (“hypospadias repair”) in the last 4 years (2016-2017, 2017-2018, 2018 – 2019, 2019-2020)? Please give specific numbers for each of the following age groups 0-4, 5-9, 10-14, 15-19 years.

AgeGroup	DiagnosisCod	DiagnosisDescription	FiscalYear			
			2017	2018	2019	2020
0 - 4	Q541	Hypospadias penile				1
	Q544	Congenital chordee		1	1	
	Q549	Hypospadias unspecified	1	1		
0 - 4 Total			1	2	1	1
Grand Total			1	2	1	1

2. How many surgical procedures have been carried out to repair post-operative urethral fistula in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)? Please give specific numbers for each of the following age groups 0-4, 5-9, 10-14, 15-19 years.

No events meet this criteria

3. What other procedures have been carried out in relation to anomalies of male genitalia including, but not limited to, procedures intended to alter the shape or curvature of the penis, or to reposition the urethra in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)? Please give specific numbers for each procedure carried out on people within the following age groups 0-4, 5-9, 10-14, 15-19.

			FiscalYear				
AgeGroup	DiagnosisCod	DiagnosisDescription	2017	2018	2019	2020	Grand Total
0- 4	Q541	Hypospadias penile				1	1
	Q544	Congenital chordee		1	1		2
	Q549	Hypospadias unspecified	1	1			2
	Q556	Other congenital malformations of penis		1			1
0- 4 Total			1	3	1	1	6
Grand Total			1	3	1	1	6

4. How many surgical procedures have been carried out in relation to reducing or adjusting clitoral size or appearance in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)? Please identify the diagnoses and give specific numbers for each of the following age groups 0-4, 5-9, 10-14, 15-19.

No events meet this criteria

5. How many surgical vaginal construction (or reconstruction) procedures were undertaken in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)? Please identify the diagnoses and give specific

No events meet this criteria

6. What other procedures have been carried out (including, but not limited to, vaginal dilation, labiaplasty, vulvoplasty, and surgery to modify the urogenital sinus) in relation to anomalies of female genitalia in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)? Please give specific numbers for each procedure carried out on people within the following age groups 0-4, 5-9, 10-14, 15-19.

			FiscalYear
AgeGroup	DiagnosisCode	DiagnosisDescription	2018
10- 14	Q529	Congen malformation femle gen NOS	1
15 - 19	Q521	Doubling of vagina	1
Grand Total			2

7. How many gonadectomies have been performed in the last 4 years? Please identify the diagnoses and the reason for removing the gonads. Please give answers broken down by age groups (0-4, 5-9, 10-14, 15-19 years) and year in which interventions took place (2016-2017, 2017-2018, 2018-2019,2019-2020).

			FiscalYear
AgeGroup	ProcedureCode	ProcedureDescription	2017
15 - 19	3064100	Orchidectomy, unilateral	1
Grand Total			1

8. If gonads have been removed from people aged under 18 years in the last 4 years, (i) in how many instances was the diagnosis confirmed using molecular genetic techniques, and (ii) over what period of time were the gonads monitored or observed using MRI prior to gonadectomy? Please give answers broken down by age groups (0-4, 5-9, 10-14, 15-19 years) and year in which interventions took place (2016-2017, 2017-2018, 2018-2019,2019-2020).

We are unable to provide you with this data as we do not hold this information in relation to MRI, and molecular genetic techniques.

9. What is the current protocol followed (in this region or hospital) in relation to the retention or removal of the gonads of people with Androgen Insensitivity Syndrome? At what ages is there consideration of: (i) the opportunity to retain gonads, (ii) the removal of gonads? (In how many instances) have removed gonads or tissue been retained for future research purposes in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)?

Any protocols relating to this procedure are managed by Wairarapa District Health Board's tertiary provider, Capital and Coast District Health Board.

10. Does the protocol (mentioned in the question above) include explicit discussion of the pros and cons of gonadectomy with people diagnosed with AIS? At what age(s) does such discussion happen, according to the protocol? Who has this discussion with the young people/families concerned (e.g., surgeon, psychologist, peer support person)? At what stage, and over what duration, is a psychologist involved?

Please refer to Capital and Coast District Health Board.

11.To whom are young people and families referred for support and information prior to gonadectomy? Please may we see a copy of the resources shared with families and individuals under these circumstances?

Not applicable. Please see above.

Please note that this response, or an edited version of this response, may be published on the Wairarapa District Health Board website no less than one week after the response has been provided to you. Any personal or identifying information will be redacted from any response published online. The DHB will endeavour to resolve any concerns you should raise but, subject to any legal grounds for withholding, ultimately reserves the right to publish any information.

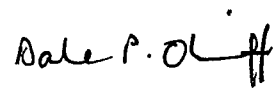
If you wish to discuss this response with us, please feel free to contact:

OIA Coordinator

Email: OIArequest@wairarapa.dhb.org.nz

Ph: 06 946 9800

Yours sincerely

A handwritten signature in black ink that reads "Dale P. Oliff". The signature is written in a cursive style with a dot above the 'i' in "Oliff".

Dale Oliff

Chief Executive