

# How are we using MyABDR? – a single HTC experience

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# RCH Statistics

- Total Patients 257
- Haem A = 113
- Haem B = 37
- Vwd = 74
- Other = 32
- Home Therapy patients = 70

# Product recording prior to MyABDR

- MyABDR started in 2014
- Prior –Spreadsheets and Pharmaceutical company apps
- 2010 Study conducted about recording Clotting factor Concentrates (CFC) at home
  - 60 Questionnaires sent out
  - 30 Questionnaires received back
  - Type of questions asked
    - How often do you record your use of CFC at home
    - How do you record
    - Who records
    - How important do you think it is to record CFC at home
    - What makes it hard to record

# Survey Results

- Results were
- 73% were happy to record all their CFC usage at home
- Most people used paper based methods
- They all felt it was important to record
- Lack of time and lack of electronic method, lack of follow up
- Follow up telephone interviews conducted about designing an electronic method
- Feedback was
  - Ease of logging in
  - Basic information recorded such as date of dose, batch number, expiry date and reason for treatment
- Centre decision to wait for MyABDR and support

# Support of HTC



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The Royal  
Children's  
Hospital  
Melbourne

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17<sup>th</sup>·March·2014·¶

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Dear·Families·¶

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Re:·MyABDR·¶

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As·you·may·already·be·aware·of·a·new·website·called·MyABDR·has·been·developed·by·the·National·  
Blood·Authority·(NBA),·the·federal·government·body·responsible·for·the·management·of·all·  
clotting·factors·in·Australia.·This·website·has·been·developed·for·people·with·bleeding·disorders·to·  
record·their·clotting·factor·usage.·This·has·a·quite·a·few·advantages·not·the·least·being·your·  
records·are·available·for·your·HTC·to·view·which·will·assist·us·with·your·child's·care.·As·part·of·  
this·website·there·is·also·a·Smartphone·app·that·can·be·downloaded·for·easy·access.·¶

As·a·treatment·centre·we·strongly·encourage·the·use·of·this·website·and·app·and·invite·you·to·  
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use·the·MyABDR·app.·We·look·forward·to·working·together·with·you·in·the·future.·¶

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Regards¶

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Dr·Chris·Barnes·¶  
Director·Henry·Ekert·Haemophilia·Treatment·Centre¶  
Royal·Children's·Hospital·¶

# MyABDR at RCH

- 92 patients registered
- 70 Home Delivery or regular treatment patients includes factor XIII, Biostate and DDAVP prophylaxis
- 22 occasional entry patients i.e. for travel or on demand use
- Of the 70 regular use patients 93% records up to date within 2 months
- 2-3 home treatment patients unable to use due to difficult circumstances (No Data or difficult family circumstances)

# Why Has This Worked!

- All HTC staff support use of ABDR/MyABDR
- HTC director and nurse refer to ABDR/MyABDR in clinic setting
- Families see the benefit of data in clinic both with ABDR and MyABDR ie physio entry of HJHS, home delivery entries. Data is valued
- When families call for clinical advice MyABDR is often referred to.

# Why Has It Worked! Cont

- MDC clinic- families have a MyABDR update
- Support supplied in regular clinic
- Liaising between patient and NBA
- Help with sign up for new patients
- Home delivery will stop if records not up to date



# NBA Help Desk

- Technical difficulties – Password issues
- Help desk enquiries

Issue category	Number of queries
Requesting access	2
Difficulty accessing	1
Forgotten login details	1
Password reset	5
Updating email address	1
Updating stock	13
Issues with application	3
Change requests	2
Recording/editing treatment	6

“As you can see, the main issues we are contacted about are on updating stock (adding or removing products) and recording/editing treatments. We find that most of these users are unfamiliar with how the system works and need assistance with adding, removing or editing a stock item or treatment. “

“If HTC’s can provide more education on the basics of how to remove and add a product to inventory and how record a treatment against a product, that would be very useful.”

# Patient Benefits

- Used in clinic room- data on bleeds
- Used for own records/inventory stock management
- Used to inform treatment regimens
- bleed management
- Communication between parents
- Non English speaking families

## Treatment Plan

Effective Date: 04 Apr 2012

Weight: 18 kg

Notes: Take Home Sheet):  
Joint/Muscle bleed dose= 750  
Next day dose= 500  
If no improvement contact your HTC

Knock to the head contact your HTC immediately. You may be instructed to give a dose of 1250  
Reviewed 04/04/2012

Recorded at: Training HTC

### Routine Prophylaxis - Advate

Frequency: 3xWeekly

Dose: No day selected - 500 IU, No day selected - 500 IU, No day selected - 500 IU

Minimum Stock Level: Not Entered

Maximum Stock Level: 18 x 500 2 x 250



Eduardo LASICH

Home

Treatments

Details ▾

Inventory ▾

Reports ▾

## Treatments

Record Treatment

## Treatment History

	<b>Bleed</b> ✎ 19 Apr 2012 - L Arm - L Forearm - Advate (500 IU)	Given Last Name(90) - 20 Apr 2012 16:11 AEST	
	<b>Bleed</b> ✎ 19 Apr 2012 - L Arm - L Forearm - Advate (750 IU)	Given Last Name(90) - 19 Apr 2012 16:09 AEST	
	<b>Routine Prophylaxis</b> ✎ Advate (500 IU)	Given Last Name(90) - 14 Apr 2012 16:07 AEST	
	<b>Routine Prophylaxis</b> ✎ Advate (500 IU)	Given Last Name(90) - 12 Apr 2012 16:06 AEST	
	<b>Bleed</b> 20 Feb 2011 - Head - Gum/Oral - Advate (250 IU)	Recorded by HTC - 20 Feb 2011	



Welcome Julia Ekert (Data Manager @ Training HTC)

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- [Transition](#)
- [MyABDR](#)

**LASICH, Eduardo**

**Patient Summary**

Status: Active  
 ABDR ID: 1361641  
 Gender: Unknown  
 Date of Birth: 13 Feb 2011 (6 years and 6 months)

**Diagnosis**

Date of Diagnosis: 13 Feb 2011  
 Diagnosis: Factor VIII Deficiency (Haemophilia A)  
 Severity: Severe  
 Base Line Factor Level: <1% as at 13 Feb 2011

**Inhibitor Testing**

Inhibitor Status: Never Present as at 04 Apr 2012  
 Latest Inhibitor Titre Level: <0.5 BU/mL as at 04 Apr 2012

**Genetic Testing**

No data

**Weight**

Weight: 18 kg as at 04 Apr 2012  
 Height: 100 cm

**Treatment Regimen**

Routine Prophylaxis - Advate Recombinant FVIII  
 3xWeekly, 500 IU, 500 IU, 500 IU, Home Therapy: Yes  
 CVAD: Not present

**Viral Status**

No data

**DDAVP Status**

No data

**HTCs**

Primary HTC: Training HTC, Training HTC

- Treatments**
- Bleeds
- Surgeries
- Stock On Hand
- Memos
- Received Products
- Discards

Treatment Date/Time	Treatment Type	Part of Body	Product	Dose	Treatment Notes
20 Apr 2012 16:11 AEST	Bleed	L Arm - L Forearm	Advate	500 IU	Follow up dose as advised by HTC
19 Apr 2012 16:09 AEST	Bleed	L Arm - L Forearm	Advate	750 IU	Fell and hit arm now not moving it.
14 Apr 2012 16:07 AEST	Routine Prophylaxis		Advate	500 IU	Prophylaxis all went well
12 Apr 2012 16:06 AEST	Routine Prophylaxis		Advate	500 IU	Right arm outside vein

# What We Have Learned

- Persistence pays off
- A united front is essential
- Present it as part of the package
- Someone has to be the MyABDR person.