Every, Juliette

From: DOWDYE, Marilyn (CENTRAL AND NORTH WEST LONDON NHS FOUNDATION TRUST) <marilyn.dowdye@nhs.net.cjsm.net>
Sent: 23 October 2017 13:02
To: Every, Juliette
Subject: [CJSM] RE: Information request on SMR
Attachments: Rotar Sara Notes from Dr Birkett.docx; Rotar Sara paed neur July 2017.pdf; Rotar Sara MRI brain scan result March 2017.pdf; Rotar Sara Maria CAF Referral form to Mosaic Sept 2017.docx

Importance: High

Hi Juliette

Please find attached the information found on this child:

Paediatrics at Royal Free Hospital - She has recently been referred and seen for assessment by Dr Ellie Day / Dulmini Birkett, Paediatricians, on 29/09/2017 – no letter is currently available from that clinic visit as yet, but have attached a brief note from Dr Birkett. Has further appointment on 19/01/2018

Paediatric Neurology letter (The Portland Hospital) July 2017 – sent as a referral to CDT Mosaic Services
MRI brain scan result March 2017
CAF referral form to CDT Mosaic Services Sept 2017

Additional email information sent from Yvonne Chung to Dr Birkett prior to the Sept 2017 clinic appointment – will be given to the paediatrician attending the EHCP meeting

BW

Marilyn

From: Every, Juliette [mailto:Juliette.Every@camden.gov.uk.cjsm.net]
Sent: 18 October 2017 17:04
To: marilyn.dowdye@nhs.net.cjsm.net
Subject: [CJSM] Information request on SMR

Marilyn,

Please find attached information request letter.

Many thanks,

Juliette Every
SEN Case Officer
SEN and Educational Psychology
Supporting People
London Borough of Camden

Telephone: 0207 974 3403
Web: camden.gov.uk

10th Floor
5 Pancras Square
London N1C 4AG

Please note that my usual working hours are:
Mon/Tues/Thurs 9:30-2:45
Wed 9:30-5:20

05/10/2017

Sara was seen in clinic last Friday so the clinic letter will not be ready in time for SPOR on next tues.

In brief:
Sara presents as a child with SLD and a motor disorder in keeping with a diagnosis of CP, GMFCS 5.
This diagnosis was shared with father on Friday.
I suspect she has equipment needs.
I think her swallow has already been assessed.
She met Madeleine on Friday.
She would require a place at Swiss Cottage school where medical care can be led by Ellie who saw Sara and father on Friday.

Regards,
Dr Dulmini Birkett

THIS IS A FACSIMILE TRANSMISSION

The Portland Hospital
for Women and Children

part of HCAHealthcare UK

The Portland Hospital for Women and Children
205-209 Great Portland Street
London
W1W 5AH
TEL: + 44 20 7390 6084
FAX: + 44 20 7390 6083
(Area code 0207 from within UK only)
Email: info@portland.hcahealthcare.co.uk
Web Site: www.theportlandhospital.com

PRIVATE & CONFIDENTIAL
For Addressee's Attention

Date:

Pages including this page:

To: Dr Kinali **Fax Number: 0207 117 3636**

From: Portland Hospital Imaging Dept

Comments

The Portland Hospital
for Women and Children
part of HCAHealthcare UK
Imaging Department

Patient Name: Maria, Rotar
Date of Birth: 14/08/2011
ID Number: X2574617
Exam Date: 14/03/2017

Dr Maria Kinali
The Portland Hospital
234 Great Portland Street
London
W1W 5QT

Examination:
MRI - MRI Imaging Review

Clinical Indication:
Acquired microcephaly. Global developmental delay. For limbs disorder with dystonia. Convergent squint.

Report:
Limited examination. There is bilateral periventricular gliosis with a minimal degree of cystic changes, associated with scalloping of the ventricles. Signal changes of the posterior limbs of the internal capsules are also noted with reduction of volume of the thalami and brainstem.

Conclusion:
Appearances are consistent with established periventricular leukomalacia.

Reported By:
Dr Wajanat Jan

(Electronically signed)

The Portland Hospital
205-209 Great Portland Street
London W1W 5AH
Imaging Reception: 0207 390 6082
Imaging Appointments: 0207 390 6081
CT and MRI Department: 0207 390 6084
Fax: 0207 390 6083
Email: imaging

The Portland Hospital
for Women and Children
part of HCAHealthcare UK
Imaging Department

Patient Name: Tveit-Auerbach, Saskia
Date of Birth: 10/05/2013
ID Number: X2577609
Exam Date: 14/03/2017

Dr Maria Kinali
The Portland Hospital
234 Great Portland Street
London
W1W 5QT

Examination:
MRI - MRI Brain

Clinical Indication:
New onset headache.

Report:
Intracranial appearances are normal.

Conclusion:
Normal examination.

Reported By:
Dr Wajanat Jan

(Electronically signed)

The Portland Hospital
205-209 Great Portland Street
London W1W 5AH
Imaging Reception: 0207 390 6082
Imaging Appointments: 0207 390 6081
CT and MRI Department: 0207 390 6084
Fax: 0207 390 6083
Email: imaging

Dr Karen I Miller
Dr. Cathryn S Katz
Dr. Marcus J Craven
Dr. Rajeev Gulati
Dr. Grace Gilbert-Kawai
Dr. R Shah
Dr. Lucinda Dunlop – Sessional GP

RECEIVED 21/7/17

Adelaide Medical Centre
111 Adelaide Road
London NW3 3RY

Tel: 020 - 7722 4135

Fax: 020 - 7586 7558

14-Jul-2017

Camden MOSAIC
Kentish Town Health Centre
2 Bartholomew's Road
LONDON, NW5 2BX

Dear Doctor

Re Miss Sara Rotar Date of Birth 14-Aug-2011
19 Lancaster Grove, London, NW3 4EX
Telephone Mobile **07459329460**
NHS Number **717 431 2217** Hospital Number

This 5 year 10 month old girl has just moved over to the UK from Romania. She has a very complex medical history. She is an ex-prem born at 32 weeks and had hypoxic ischaemic injury at birth requiring mechanical ventilation. There is also a history of phototherapy for neonatal jaundice although there is no information about the bilirubin levels. She has been diagnosed as having global developmental delay with mixed pyramidal and extra pyramidal elements. She has an alternating convergent squint, failure to thrive and significant constipation. This list was compiled following a private review under the care of Dr Maria Kinali, Consultant Paediatric Neurologist. I attach her lengthy and thorough assessment for your information. Apparently MRI imaging led to a diagnosis of peri-ventricular leukomalacia. She has been reported as having a number of startling episodes but no specific seizures.

Dr Kinali recommended starting her on Trihexyphenidyl liquid as well as Movicol. As you can see from her assessment she has very significant needs around her developmental delay and I am sure that she needs to be under the care of the Camden MOSAIC service as well as general paediatrics and she may well need some onward referrals to ophthalmology and an NHS based paediatric neurology service.

I am sending this referral letter to both MOSAIC and general paediatrics at the Royal Free Hospital to begin the process of arranging her care under the NHS.

Many thanks for arranging to see her.

Yours sincerely

MARCUS CRAVEN

Maria Kinali MD MRCPCH
Consultant Paediatric Neurologist
Honorary Clinical Senior Lecturer, Imperial College London

Chelsea and Westminster Hospital
369 Fulham Road
London SW10 9NH
Tel: 0208 746 8000 (Switchboard)
Fax: 0207 117 3636
E-mail: paediatricneurology@drkinali.com

BUPA Cromwell Hospital
162 Cromwell Road
London SW5 0TU
Tel: 0207 460 5700
Fax: 0207 835 2419

The Portland Hospital
205-209 Great Portland Street
London, W1W 5AH
Tel: 0207 580 4400
Fax: 0207 390 8012

Jacqueline Gore PA: 07581 046963 BUPA provider number: 04077471

13th March 2017

Name:	Sara Maria Rotar
DOB:	14/08/2011
MRN:	X2574617
Date Seen:	13th March 2017 as a new patient consultation at the Portland Hospital and 16th of March 2017 as a followup consultation at the Cromwell Hospital

Problems/Diagnoses:
- Ex-prem 32 weeks' gestation with hypoxic ischaemic injury at birth requiring mechanical ventilation and phototherapy for two days for neonatal jaundice
- Global developmental delay with mixed pyramidal and extrapyramidal elements
- Alternating convergent squint
- Dyslipidaemia (unsubstantiated)
- Failure to thrive and ongoing drooling
- Significant constipation

Current Medications:
Nil

Medications:
- To start on Trihexyphenidyl liquid in the following manner:
  Week 1: 1 mg twice daily
  Week 2: 1 mg three times daily and
  To continue increasing every week by 1mg until 2 mg three times daily
- Movicol paediatric sachet one a day to be increased as required depending on response
- GTN paste topical for anal fissure

Most Pertinent Neurology Investigations:
- Second opinion of the brain MRI study (carried out in Romania). This is a limited examination. There is bilateral periventricular gliosis with a minimal degree of cystic changes, associated with scalloping of the ventricles. Signal changes of the posterior limbs of the internal capsules are also noted with reduction of volume of the thalami and brainstem. The appearances are consistent with established periventricular leukomalacia.
- Other investigations from foreign source – acetylcarnitine 8.8 low (normal 12.3 and above), propionylcarnitine low 0.44 (normal 1.4 and above), butyrylcarnitine elevated 6.05 (normal less than 1.5) and decanoyl carnitine 0.05 low (normal 0.9 and above), cholesterol 270 mg (normal less than 200) with normal glucose, full blood count normal,

repeat cholesterol 204 borderline normal, plasma amino acids normal with low cysteine 0.2 (normal greater than 0.5) and elevated serine (normal up to 1.9), total carnitine in serum 17.3 (elevated normal up to 53.3) and free carnitine in serum 54.3 (elevated, normal up to 45.5).

Auxology:
Weight 11.8 kg (below the 0.4th centile)
Supine length 97.5 cm (below the 0.4th centile)
OFC 43.5 cm (below the 0.4th centile)

Auxology at Birth:
Weight 1.35 kg (9th centile)
OFC 29 cm (25th centile)

It was a pleasure to meet up with Sara Maria and her parents in my new patient neurology clinic. I have reviewed her once more with the results of her brain MRI study that was reviewed in London previously carried in Romania. Her parents are visiting London. Sara Maria has no overarching diagnosis and they are also seeking a solution in terms of treatment. They reported that they are likely to stay in the UK longer trying to seek permanent employment and Sara Maria eventually to be looked after in the National Health System.

Sara Maria is a nearly 5-1/2-year-old girl. She was the product of a pregnancy complicated with hypertension around the fourth month, proteinuria and limb oedema. Mother reports foetal movements that were normal and some suggested abnormalities on the Doppler ultrasound scans. She was delivered at 32 weeks' gestation by a caesarean section and she was at breech presentation. She weighed at birth 1.35 kg and her Apgar scores were 6, 7 and 8. She was resuscitated and required mechanical ventilation for two weeks. She had a phototherapy for two days (it is unclear of the level of the bilirubin). She had a cranial ultrasound scan which diagnosed her with periventricular leukomalacia. She was hospitalised for one month. Despite the findings on the cranial ultrasound scan parents claim that they were not initially referred to the paediatric neurologist. For the first five months since birth she had no head control and preferred to keep her hands fisted. She was irritable and crying as if she was in pain. She had frequent arousals at night with back arching but with no vomiting. Parents reported that they noticed also that she had a number of startling episodes but no seizures as such. Her eyes started crossing over. She did not develop a social smile on time and needed to be consoled constantly. They report that she had some floppy episodes but her tone was normal between them. They reported that she had anti-gravity power of the upper and lower limbs but not quite good control.

She has also had ongoing drooling with a lot of tongue thrusting. She was bottle-fed without really gaining weight. About two years ago, she started on a new milk which parents have to source from Germany.

At around the age of five months she was referred to paediatric neurology when she was diagnosed with severe global developmental delay and had subsequently the diagnosis of bilateral periventricular leukomalacia. She has been having various therapies, physiotherapy including Bobath with limited benefit.

Currently she is unable to sit unaided but started sitting with support since the age of 4-1/2. She is able to roll over from her side and her back. She is also able to roll back from the front. Parents reported she has improved cognition. If interested she can also control her head briefly. She keeps her hands fisted intermittently. She is able to grab hold of the napkins, chargers, and is also mouthing. She has an overall happy demeanour. Her father thinks that she has very good receptive language and says yes and no and grandma. She

tends to swallow her foods without necessarily chewing it. Currently, this is offered finely chopped or mashed. She seems to like foods that melt in the mouth. With regards to her liquids she drinks from a bottle with a special teat. She had delayed oropharyngeal phase presumably and there is often pooling of water out of her mouth.

She has also had longstanding constipation and was on probiotics. During this visit her father tells me that she developed an anal fissure.

She has not had any lower respiratory tract infections and had normal vision and hearing. Her skin is without any birthmarks and immunisations are up-to-date. Parents reported that she has had dyslipidaemia. This has been identified on a number of blood tests.

Parents say that she has had some investigations sent off to Germany and on their second visit with me in clinic they brought her results of her full carnitine profile and cholesterol studies. These showed some abnormalities including two of her plasma amino acids.

She had thrice brain MRIs, the last one was three months ago, and was available for us to review in London. Apparently, she has had longstanding issues with her teeth and has had a normal karyotype. Her OFC at birth was 29 cm and currently is 43.5 cm.

From the family history Sara Maria is the only child of her parents together. Father is 42 years old and mother is 46. She has a 20-year-old daughter from a previous relationship who is healthy and he has a 21-year-old son who is healthy. Prior to having together Sara Maria, mother had a miscarriage at six weeks' gestation. There is no family history of relevance over both sides of the family over three generations. However, mum's brother spoke late when he was aged 4.

Sara Maria is not on regular treatment. However, in the last three years she had Coenzyme Q10 at 30 mg twice daily and also some enzyme treatment as she used to failure to thrive.

On examination, Sara Maria has a very pleasant predisposition and a happy demeanour and tends to laugh a lot. She has a strikingly limp phenotype with normal head, and peg shaped teeth. Her palate is normal. She displayed a lot of tongue thrusting and her jaw jerk is positive. She was dribbling intermittently. She has mixed hypertonia of the upper and lower limbs, which is worse on the left with extrapyramidal signs. This is clearly demonstrated on her posture of her upper limbs with intermittent fisting and also on the repertoire of her movements. She has clonus on the left leg. Deep tendon reflexes are brisk and she has upgoing plantars. She has abnormal position of both teeth. She has abnormal nails on toenails particularly on both big toes and some overlapping toes and abnormal foot posture. She has peg-shaped teeth.

I have since met with her father to discuss the results of her brain MRI and also the way forward. Our review of the original brain MRI study confirms that this is a periventricular leukomalacia, which is quite advanced with bilateral thalamic involvement. This does not look like a progressive disease and there is certainly no cortex involvement. This is in relation to some of the original brain MRI studies that suggested that she has normal thalamic appearances and also that suggested that she has some cortical involvement which is not necessarily the case. The present study therefore excludes the possibility that there is neuronal migration abnormality. Whether there is also any associated metabolic defect, this is a further discussion. There is certainly enough evidence from the presenting history to suggest that the findings are in keeping with periventricular leukomalacia in terms of the prematurity. Also, the active resuscitation at birth and perinatal events would put more emphasis on the bilateral hypoxic ischaemic changes that we see on the current MRI study. I explained that periventricular leukomalacia or neonatal disease of prematurity is due to injuries/damage on the white matter. I explained that white matter tends to develop in the

brain from conception but clearly initiates around the fifth month of the pregnancy and continues until the first two years of life when it is largely completed although some further maturation may happen even in the adult years. On the basis of that, one would expect at the current MRI findings that Sara Maria will have problems with her movement, the control of the movement and also in the cognitive domain and also in the speech. The children who have a dyskinetic picture as she does may have actually better cognition as it is the case with her. She has significant swallowing difficulties and the worry is about ongoing failure to thrive. Father tells me that he is hoping to remain in the UK and get her into the National Health System where she will be looked after under a neuro-disability centre. She is likely to have a number of input for example speech and language therapy, occupational therapy, physiotherapy and also reviewed by orthopaedic colleagues in terms of the posture and the tone of her legs and also gastroenterology in terms of her ongoing gastrointestinal (severe constipation). From the medical management, I would recommend that she starts on trihexyphenidyl and I instructed the father how to introduce the medication and how to continue increasing it. I discussed the side effects of these medications and I would like to review her in the next four weeks in clinic to check on her progress. He will also have the opportunity to give me an update about their status in the UK at that point. I have also prescribed her Movicol.

Yours sincerely

Checked and signed electronically

Dr Maria Kinali
Consultant Paediatric Neurologist

Copy:
Parents

CAF Referral

Camden

Consent for information storage and sharing

This form relates to (child name) Sara Maria Rotar

Consent must be obtained for CAF to proceed except in the following circumstances;
a) where there are clear child protection concerns i.e. child has an actual injury and or has made allegations against their parent/carer
b) when the referrer suspects that by attempting to get consent from the parents that this could potentially place the child/ren and or the adult victim at potential risk of harm
c) when the referrer has sought consent but the parent/carer has refused permission. In this instance the referrer believes that by not sending the referral to FSSW then the identified concern(s) are likely to escalate and may place the child/ren at further risk of potential harm.

I understand the information that is recorded on this form and that it will be stored and used for the purpose of providing services to:

☐ Me ☑ This infant, child or young person for whom I am a parent / carer

I have had the reasons for information sharing explained to me and I understand those reasons
Note that social worker may undertake a network check.

I agree to the sharing of information other than those services listed below

O ✓Yes O No

(Practitioner to detail if any information should not be shared with particular agencies)

Signed

Yvonne Cheung

Parent has not consented for the following reason:

Child, Family and Service information

Child/young person details

First names	Sara Maria
Last name	Rotar
Date of birth	14/08/2011
NHS ID	717 431 2217
UPN ID	
Gender	Female
Address	Flat 14, 19 Lancaster Grove, London NW3 4EX
Ethnicity	Romanian
Religion	
Language spoken	Romanian, English

☐ Interpreter/signer required

Presenting issues

At least one presenting issue MUST be selected. If multiple issues have been identified select all that are applicable

☐ Alcohol
☐ ASB

ASB - Describe briefly

☐ ✓Disability
☐ Domestic violence
☐ Drugs
☐ Families in acute stress
☐ Financial problems
☐ Gangs
☐ ✓Housing
☐ Ill health
☐ Child mental health
☐ Parental mental health
☐ Missing child
☐ ✓Missing Education

For children missing education please select reason for this: Recently moved to UK. Previously did not attend school in Romania as there were no schools that could support Sara Maria.

Other reason for missing education

☐ Neglect and Abuse
☐ Parenting support
☐ ✓AEN

AEN - Describe briefly

Learning and physical disability; Speech & Language impairment.

Information from private consultant @ Portland Hospital. Global Developmental Delay, Periventricular Leukomalacia, Mixed Hypertonnia – Upper and lower limbs. Failure to thrive and ongoing drolling.

- ☐ Sexual exploitation
- ☐ Trafficked children
- ☐ Unaccompanied minor
- ☐ Young carer
- ☐ Other - please specify

Other presenting issue

Has been provided with the following equipment from Romania which requires review:

Wheelchair, orthotics, spinal brace

Please include parents or others who have a caring role for the child/young person, siblings and any relevant extended family and step family members and all relevant contact numbers.

Household members and other significant adults

Name	Date of Birth	Gender	PR	Ethnicity	Address	Religion	Relationship to child
Stefan	unknown	M	yes	Romanian	Flat 14, 19 Lancaster Grove, London NW3 4EX		Father
Maria	unknown	F		Romanian	As above		Grandmother
Brother	unknown 21yrs old	M		Romanian	As above		Half Brother

Family Contact Numbers:

Father: 07459 329 460

Lead Professional (if known)

Lead Professional's Name	Yvonne Cheung
Job Title	Integrated Care Support Team
Contact Number	07525800516
Contact e-mail	Yvonne.cheung1@nhs.net

School / preschool attended

Name	n/a
Address	would be appropriate for Swiss Cottage School
Postcode	

Please add details about universal services including school and GP in the table below
Telephone, e-mail address, address.

Services involved

Name	Agency	Contact details
Sheila McQuaid	Homelessness Prevention Adviser	Sheila.McQuaid@camden.gov.uk
Dr Marcus Craven	GP	Adelaide Medical Centre 0207 722 4135
Dr Dulmini Birkett / Dr Ellie Day	Consultant Paediatricians (awaiting Ax)	Royal Free Hospital
Alison Montgomery	Clinical Co-Ordinator of Speech and Language Therapy in Camden MOSAIC	07825 340 937 alison.montgomery2@nhs.net

Referral Information

Referral Date	25th September 2017

Details of person making referral

Name	Yvonne Cheung
Organisation	Integrated Care Support Team
Job Title	Clinical Assessment & Care Planning Co-ordinator
Contact telephone number	07525800516
Contact e-mail	Yvonne.cheung1@nhs.net

Referral Information

Information is mandatory.

What has led to this unborn baby, infant, child or young person being referred?

Why the case came to our attention, why we are concerned and why our involvement is required This section:

- Must be written in plain English with no jargon e.g. Merlin, sec 47 etc
- Should succinctly explain what the detail of the referral was (the presenting issues) and the sources of information
- Must clearly tell the family what the issues are and why intervention is required.

The family are currently living in a one room studio flat which is not suitable for Sara Maria's needs.

Sara Maria is not yet attending any educational facilities.

Family would benefit from advice on support and services available to them e.g. short breaks or activities that she may be able to access in the meantime whilst we try to move forward with an Education, Health and Care Plan application.

What has been done to date?

What work has been carried out with the family to date.

Joint assessment carried out with Dysphagia Outreach Team and Integrated Care Support Team.

Awaiting assessment with Neurodisability clinic on Friday 29th Sept 2017.

Referral to KIDS service made today.

What are the strengths/protective factors in the family?

Father is very protective towards Sara Maria's well-being since separating with mother who remains in Romania. He has found work and is proactive in looking for adequate housing to provide for Sara Maria's needs. He is keen for her to be attending a school that can meet her needs.

Grandmother is here to help look after Sara Maria whilst father is at work and a strong bond between them was observed during the visit.

Referral Outcomes

- ☐ Accepted as a referral
- ☐ Pending because more information required
- ☐ Refused as it does not meet service access criteria
- ☐ Referral does not meet threshold and has been referred to:

_____

Signed

Yvonne Cheung