

PATIENT INFORMATION: A GUIDE TO YOUR CHILD'S MIBG SCAN

This information leaflet from the Royal Belfast Hospital for Sick Children (RBHSC) will explain what a MIBG scan is and why your child has been sent for one. Please read this leaflet carefully. If you have any questions or concerns not answered by this leaflet, please contact the RBHSC Radiology department (Telephone: **028 961 50289**).

What is a MIBG Scan?

A MIBG scan is a special test that looks for neuroblastoma cells using a special 'dye' called an isotope. These cells are found in tumours that affect the nervous system. It can show up the original tumour as well as any cells that have travelled to other areas of the body. This scan takes place over 3 days. The first day your child will receive an injection of the isotope. The second and third days your child will have whole body scans.

What are the benefits of having a MIBG scan?

This scan is the best scan to show the presence of any Neuroblastoma cells throughout your child's entire body. The isotope that is injected travels around your child's body and sticks to any abnormal areas, showing up as 'hot spots' on the scan pictures.

If you choose not to proceed with the test, it is important that you let your child's doctor know. It may delay any treatment that is planned for your child.

What are the risks?

MIBG scans use a type of radiation called ionising radiation, which can be damaging to the body at high levels. Everybody is exposed to radiation from the world around us: this is known as background or natural radiation. One way to measure the dose of radiation from a Nuclear Medicine exam is to work out how many months of background radiation it is equivalent to.

The radiation dose from this scan is similar to the natural radiation exposure your child would receive in just over 2 years. This exposure to ionising radiation represents a very low risk to your child of developing a cancer in the future. The small risk is outweighed by the greater benefit of having the scan.

You will be advised to follow some radiation protection instructions in the 48 hours after the scan to further reduce the dose to you and your child.

Are there any alternatives?

Other imaging tests such as Ultrasound, CT, x-rays and MRI can be used to look for abnormal cell growth. These examinations tend to be specific to one area and do not look at the entire body in one scan. These alternative tests are often used alongside MIBG scans to give the maximum amount of information on your child's condition.

Before your child's appointment

Please phone to confirm that you will be attending the appointment as failure to do so may result in your appointment being cancelled

If you are pregnant or think you may be, please contact the Radiology Department at least 2 days prior to your child's appointment. There is a small risk that the isotope given to your child may harm your unborn baby, so we advise you to organise another adult to help look after your child for the 48 hours after the scan, if this is not possible we may have to reschedule the appointment.

All children 10 years or older will be asked about their periods and any possibility that they could be pregnant. Patients will be required to sign a form stating that they are not pregnant before the examination can proceed. Please inform the Radiology Department if your child's period falls outside of its normal cycle on the appointment date, as it may need to be rescheduled.

If the person who is bringing your child does not have Parental Responsibility, please ensure that the person/s that do complete the Consent form at the end of this leaflet, and it is brought with the child to the examination.

Before your child's procedure

There are some medications/drugs that may interfere with the scan, the referring doctor will tell you if your child need to stop taking any medications before the scan.

The isotope used in this examination contains iodine. This would normally be taken up by your child's thyroid gland, however, we want to prevent thyroid uptake. Potassium iodate tablets will need to be taken, the day before and the day of the isotope injection. The referring doctor will organise the supply of these tablets.

There is no special preparation for the MIBG scan itself, although we encourage your child to be well hydrated (not thirsty), so please make sure that they have plenty of water/non-fizzy juice throughout the day of the scan. You can expect to be at the hospital for up to 2 hours each day so you may want to bring some toys or books to keep your child entertained.

Will my child feel any pain?

Your child will have to have an injection for this scan. We can use anaesthetic “magic” cream before the injection to numb the skin. We also have a “magic” cold spray which we can use just before the injection. The cream takes 30-40 minutes to work and is very effective, the spray works immediately but doesn’t always block out all the pain.

Unfortunately, neither the cream nor the spray can be used on children under 6 months old, but we can give them some sugar solution, which can soothe babies.

If your child has a central line, we can administer the isotope through this under the supervision and aide of a trained Staff Nurse in the Oncology/Haematology department.

On the Day of the Scan

Please attend the department at the time on your letter. We would politely request that only one adult accompanies the patient.

If you do not wish to go ahead with the procedure or are undecided, please let the radiographer know so that they can answer any questions you may have. Remember, **it is your decision**. You can change your mind at any time during the procedure and your wishes will be respected. Not having the procedure, however, may delay the diagnosis and treatment of your child.

When you report to reception, the “magic” cream will be applied to your child’s hands, elbows and occasionally feet, if your child does not have a central line in place

Once the “magic” cream has made your child’s skin numb, a member of staff will call you to the Nuclear Medicine department where they will be weighed.

The cream will be taken off and the child will lie up on a bed and they will be offered a book to distract them.

The radiographer will ask you if you are happy for the procedure to go ahead. This is a form of verbal consent. You can still change your mind at any point.

The radiographer will inject the isotope via a small needle, which is removed immediately after or the patient’s central line. This is done very slowly over 5 minutes and can be uncomfortable. The injection has to be given slowly in case the child has a reaction to the isotope such as a sudden drop in blood pressure.

Your child is scanned at 24 and 48 hours post injection. You will be given a time to return for the scan on these two consecutive days. You can leave the hospital during this time. The scan can take up to one hour, depending on the height of your

child. The camera heads travel from your child's head to their toes while they are lying on their back. The camera head does come quite close to your child's body throughout the scan but will not touch them. You can stay with your child throughout the scan. For younger children, we will try and plan around sleep times or during bottle feeds. Once the child's head has been imaged the child can be fed while lying on the bed. We also have a DVD player with a small selection of DVDs. If your child has a favourite DVD, they can bring it with them.

What happens after my child's MIBG scan?

At the end of the test, your child is free to go home.

The isotope becomes inactive in the hours following the scan and is passed out of the body in your child's urine (wee).

It is important after the scan to follow these post-procedure instructions for 48 hours:

- If your child is in nappies, you should change them frequently and place the used one in the outside bin, please wash your hands thoroughly after changing the nappy.
- If your child is potty training, flush the toilet twice after emptying the potty. Wash the potty and your hands with soap and water.
- If your child is toilet trained, your child should flush the toilet twice. If your child requires assistance with toileting, please ensure that both you and your child wash their hands well with soap and water.
- If your child accidentally wets their clothes or bedding, put them in a separate bag for 48 hours and then wash them as normal.
- If you or someone in your household is pregnant, you should avoid close contact with your child after their injection and for 24 hours after. This is to protect the unborn baby from the effects of the radiation.
- We encourage your child to drink more than usual after the scan
- Your child can continue to take any medicines as usual. The isotope will not affect them in any way.

When will I get the results of the MIBG scan?

The Radiologist will write a formal report. This report can be accessed by the Doctor who referred your child usually within 10 days. You will be able to discuss the results and treatment options with the referring team at your child's outpatient follow up appointment.

Image sharing

Your images will be electronically stored on the hospital picture archiving system. This data can be accessed throughout the Belfast Health and Social Care Trust and other doctors and health care professionals who are directly involved in your care.

The ability to share images and radiological reports will improve the safety and quality of your care by ensuring that the right information is available in the right place at the right time.

In order to improve the medical services we provide we may also use your data as anonymously as possible for internal audit and medical education. If you would prefer that your data is not used for these purposes, please inform a member of staff when you attend for your examination.

If your data is to be used for research, then a separate consent process will be used. You will be asked for your consent, should this be the case.

Contact us

If you have any queries, we will be happy to answer any questions on the day of your scan or you can contact us on the number given on your appointment letter.

Feedback

We hope you found the information in this leaflet helpful. If it did not tell you what you needed to know or you would like to provide any feedback on your experience please let us know so that we can make any necessary improvements.

You can provide feedback on your experience:

Telephone: **028 9504 8000** (Monday-Friday: 9am-4pm)

Textphone: **18001 028 950 48000**

By email: compliments@belfasttrust.hscni.net

By email: complaints@belfasttrust.hscni.net

By completing an online form:

<http://www.belfasttrust.hscni.net/contact/FeedbackForm.htm>

Care Opinion



We invite you to share your experience by clicking the following link:

<https://www.careopinion.org.uk/>

or by scanning the following QR code on your smartphone or tablet:



Language and accessible support services -

Deaf/Hard of Hearing

If a Sign Language interpreter is required, please either telephone **028 9615 8900** via the Sign Video remote interpreting service (<https://signvideo.co.uk/deaf-community/>) or email us at MPHAdminFOH@belfasttrust.hscni.net and we will arrange one for your appointment. Please have your H&C number ready when calling or include it in your email. This can be found at the top right corner of any Health and Social Care letters you may have received.

If you are unable to hear on the phone and need to contact us with regards to your appointment you can email us at MPHAdminFOH@belfasttrust.hscni.net.

Do you need this information in another format or language?

The Trust has access to interpreting and translation services. If you need this information in another language or format, including Braille, large print, CD, audio tape please contact the telephone number **028 9615 8900** or e-mail address MPHAdminFOH@belfasttrust.hscni.net, and we will do our best to meet your needs.

Polish - Czy potrzebujesz tych informacji w innym formacie lub języku?

Fundusz ma dostęp do usług w zakresie tłumaczeń ustnych i pisemnych. Jeśli potrzebujesz tych informacji w innym języku lub formacie, w tym w piśmie Braille'a, dużym druku, na płycie CD, kasecie magnetofonowej, skontaktuj się z nami pod numerem telefonu lub adresem e-mail **028 9615 8900 / MPHAdminFOH@belfasttrust.hscni.net**, a my dołożymy wszelkich starań, aby spełnić Twoje potrzeby.

Arabic - هل تحتاج هذه المعلومات بصيغة أو بلغة أخرى؟

تستطيع الجمعية توفير خدمات الترجمة الفورية والتحريرية. إذا احتجت هذه المعلومات بلغة أو بصيغة أخرى، بما فيها أو في شريط مسموع، يُرجى الاتصال برقم **CD** أو صيغة بالأحرف الكبيرة، أو في سي دي **Braille** بصيغة برايل MPHAdminFOH@belfasttrust.hscni.net / **028 9615 8900** عبر البريد الإلكتروني، وسوف نبذل قصارى جهدنا في تلبية احتياجاتك.

Lithuanian - Ar jums reikia šios informacijos kitu formatu ar kalba?

Tarnyba gali suteikti vertimo žodžiu ir raštu paslaugas. Jei reikia šios informacijos kita kalba ar formatu, įskaitant Brailio raštą, didelį šriftą, kompaktinį diską, garso

įraša, skambinkite telefonu arba susisiekite el. paštu
MPHAdminFOH@belfasttrust.hscni.net / 028 9615 8900 ir mes padarysime viską,
kad patenkintume jūsų poreikius.

Romanian - Aveți nevoie de aceste informații într-un alt format sau altă limbă?

Trustul are acces la servicii de interpretariat și traducere. Dacă aveți nevoie de aceste informații într-o altă limbă sau într-un alt format, inclusiv Braille, tipărire cu caractere de mari dimensiuni, CD, înregistrare audio, atunci vă rugăm să ne contactați la numărul de telefon sau la adresa de e-mail
MPHAdminFOH@belfasttrust.hscni.net / 028 9615 8900, iar noi vom face tot posibilul pentru satisfacerea necesităților dumneavoastră.

Tetum - Ita presiza atu informasaun ida ne'e iha formatu ka lian seluk ka lae?

Fidusiáriu ida ne'e iha asesu ba servisu durubasa no tradusaun. Se Ita presiza informasaun ida ne'e iha lian ka formatu seluk, inklui letra Braile, letra boot, CD, kasete audio, entaun favór telefone número ka enderesu e-mail
MPHAdminFOH@belfasttrust.hscni.net / 028 9615 8900, no ami sei halo esforsu tomak atu kumpre Ita-nia nesesidade sira.

CONSENT FORM

I confirm that I allow my child _____ to have this MIBG scan and associated injection. I am aware of the benefits, risks and aftercare required.

In the event of any issues that may arise, I authorise the person detailed below to act in the best interests of my child.

Name of person accompanying the child _____

Relationship to the child _____

Parental Signature _____ Date: _____

Contact us

If you have any concerns about your child having a MIBG Scan, please contact the Radiology Dept **028 9615 0289**

Your comments and concerns:

References:

1. Nuclear Medicine MIBG Scan [Internet].; 2018 [updated September; cited 21 May 2020]. Available from: <https://www.surreyandsussex.nhs.uk/wp-content/uploads/2018/10/Nuclear-Medicine-MIBG-Scan.pdf>.
2. Your Child's MIBG Scan [Internet].; 2017 [updated 13 July; cited 21 May 2020]. Available from: https://www.ruh.nhs.uk/patients/services/clinical_depts/nuclear_medicine/documents/patient_leaflets/Child_MIBG.pdf.
3. MIBG Scan: Information for parents and the carers [Internet].; 2018 [updated February; cited 21 May 2020]. Available from: <https://www.ouh.nhs.uk/patient-guide/leaflets/files/11618Pmibg.pdf>.
4. MIBG scan [Internet].; 2016 [updated October; cited May 21, 2020]. Available from: <https://www.gosh.nhs.uk/medical-information/procedures-and-treatments/mibg-scan>.