

MANCHESTER TEACHING AND RESEARCH FOR RARE DISEASE GROUP (MANTRRA)

England & Wales · Charity number 1180101

Details

Status Registered

Legal form CIO

Registered 2018-09-27

Register [View on the Charity Commission register](#)

Contact

Address Manc. Centre for Genomic Medicine
St Mary's Hospital
Oxford Road
Manchester
M13 9WL

Phone 01617010980

Email Siddharth.Banka@mft.nhs.uk

Activities

Objects: THE OBJECT OF THE CIO SHALL BE TO ADVANCE AND PROMOTE THE SCIENCE AND MEDICAL PRACTICE OF RARE DISEASE GENOMIC MEDICINE FOR THE PUBLIC BENEFIT BY:- PROMOTING EDUCATION IN RARE GENETIC DISEASES , SUPPORTING THOSE WHO HAVE AN INTEREST IN THIS AREA SO THAT THEY MAY BE AIDED IN THEIR JOINT ENDEAVOURS TO DIAGNOSE, UNDERSTAND, PREVENT, ALLEVIATE AND CURE CONGENITAL MALFORMATIONS AND CONDITIONS WITH A GENETIC AETIOLOGY; - SUPPORTING AN INTERNATIONAL RARE DISEASE MEETING AT LEAST EVERY TWO YEARS;- SUPPORT TRAINING IN THE FIELD OF RARE DISEASES THROUGH BURSARIES AND SCHOLARSHIPS- CARRY OUT RESEARCH AND PRODUCE AND DISSEMINATE REPORTS, STATEMENTS, AND RESEARCH FINDINGS

Activities: The object of MANTRRA is to advance and promote the science and medical practice of Rare Disease Genomic Medicine. It will further education who in Rare Genetic Diseases , supporting those who have an interest in this area so that they may be aided in their joint endeavours to diagnose, understand, prevent, alleviate and cure congenital malformations and conditions.

Classification

- **How:** Makes Grants To Individuals, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Defined Groups, The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-01	-	-	-	-
2024-04-01	£0	£882	-	-
2023-04-01	£0	£312	-	-
2022-04-01	£3,550	£0	-	-
2021-04-01	£7,000	£0	-	-
2020-04-01	£16,384	£9,436	-	-

Trustees

Name	Role	Appointed
Dr Jill Clayton-Smith		2018-01-01
Dr SIDDHARTH MANISH BANKA		2018-01-01
SOFIA DOUZGOU HOUGE		2018-01-01

Accounts

MANTRRA: “MANchester Teaching and Research for RAre Disease

Annual Report

March 9th 2025

1. Introduction

MANTRAA was set up as a CIO in September 2019. The main objectives of the CIO are to advance and promote the science and medical practice of Rare Disease Genomic Medicine. To this end MANTRAA aims to:

1. Further education in Rare Genetic Diseases, supporting those who have an interest in this area to diagnose, understand, prevent, alleviate and cure congenital malformations and rare genetic disorders
2. Support rare disease meetings, specifically the biannual Manchester Dysmorphology Conference. The first one was organized in 1984 by Professor Dian Donnai. Over the years, this biennial conference has brought experts within the field of genomic syndromology together from around the globe, to share knowledge and ideas which further our understanding of developmental disorders and congenital malformations. The conference aims to provide cutting edge content and a welcoming, relaxed setting to encourage discussions, forge collaborations and inspire new ways of improving the lives of patients.
3. Support training through bursaries and scholarships
4. Aid the collation and dissemination of reports, statements and research findings

2. Changes to Trustees 2024-2025

Jill Clayton-Smith ended her membership. Sofia Douzgou Houge (SDH) is resident in Bergen, Norway. All trustees agree to close the charity within the following financial year.

3. Activities February 2024- February 2025

- a) **AGM.** Because of a busy schedule around point 3c), and on-going discussion around closing the charity (see point 2), the AGM took place over mail correspondence.
- b) **Annual reports.** Trustee members received notification about a delayed annual report on Friday 7th March 2025, SDH circulated the 2024-2025 report on March 9th, 2025, and will submit asap.

c) Meeting support

The 2024 Manchester European Society of Human Genetics (ESHG) Syndromology and Dysmorphology Course: the course was held in Manchester, October 22nd- 24th, 2024. It was advertised on the ESHG website, the Manchester Rare Conditions Centre (MRCC) website and on relevant social media platforms. We reviewed 134 applications and 74 national, and international (Manchester to Hong Kong) attendees were offered participation. Speakers (18) from countries across the European continent were invited. Feedback from attendees was very positive with an average rating around overall organization of the course 4.79/5.

We have had some discussions with Dr Grace Vassallo and Dr Gareth Evans who hosted the Euro NF1 and NF2 conference in 2022. Neurofibromatosis 1 and 2 are multisystem disorders, with NF2 being very rare. Individuals with these disorders need specialist care and its important to train GPs and other doctors to both recognise signs of these disorders and to be able to help with specialist management. We have agreed to support educational initiatives in the future, particularly training expenses for doctors.

d) Education

We continue to contribute to other educational initiatives through our links with the European Reference Network for Congenital Anomalies, ERN ITHACA. SB and SD have continued to participate in teaching activities in Europe, the UK and overseas. ERN ITHACA sponsored fellowships for the ESHG and MRCC course too.

e) Collation and dissemination of reports, statements and research findings

We continue to contribute to publications for rare conditions in the scientific medical literature.

4. 2025-2026 Plans

- a) Scientific support of the Manchester Dysmorphology Conference November 2025
- b) Continue with meeting support liaison for the Manchester NF1/NF2 group
- c) Closure of the charity

5. Accounts

These were verified over email.

We declare no further income this year.

We will have to pay an accountant for audit as per the Charity commission rules. That charge will be added to our account later.

Our expenditure was for support for NF team (see point 3c).

Date	Item		Receipt	Expenditure
February 2024	Starting balance	£39,194.05 of which £9,472.00 donation from Convenzis Group (NF conference net income)		
November 2023	Transfer to Dr G Vassallo for NF1 MDT expenses	-£312,31		

April 2024	Transfer to Dr G Vassallo for NF1 MDT expenses	-£269,90		
November 2024	Transfer to Dr G Vassallo for NF1 MDT expenses	-£299,35		
Totals		£38,312.44 of which £8,590.44 NF fund		

BALANCE £38,312.44 as of February 2025

Report compiled March 2025 by Sofia Douzgou Houge and Siddharth Banka

Accounts

MANTRRA: “MANchester Teaching and Research for RAre Disease

Annual Report

April 6th, 2024

1. Introduction

MANTRAA was set up as a CIO in September 2019. The main objectives of the CIO are to advance and promote the science and medical practice of Rare Disease Genomic Medicine. To this end MANTRAA aims to:

- a. Further education in Rare Genetic Diseases, supporting those who have an interest in this area to diagnose, understand, prevent, alleviate and cure congenital malformations and rare genetic disorders
- b. Support rare disease meetings, specifically the biannual Manchester Dysmorphology Conference. The first one was organized in 1984 by Professor Dian Donnai. Over the years, this biennial conference has brought experts within the field of genomic syndromology together from around the globe, to share knowledge and ideas which further our understanding of developmental disorders and congenital malformations. The conference aims to provide cutting edge content and a welcoming, relaxed setting to encourage discussions, forge collaborations and inspire new ways of improving the lives of patients.
- c. Support training through bursaries and scholarships
- d. Aid the collation and dissemination of reports, statements and research findings

2. Changes to Trustees 2023-2024

No changes to Trustees. Sofia Douzgou Houge (SDH) is resident in Bergen, Norway. Ongoing discussions regarding the appointment of further trustees (invited but not yet accepted).

3. Activities February 2022- February 2023

- a. **AGM.** Our AGM was held on October 17th, 2023.
- b. **Annual reports.** SDH circulated a 2023-2024 report late and will submit asap.

4. Meeting support

The 2023 Manchester Dysmorphology Conference: From October 16th to October 18th, 2023, the Hilton Deansgate in Manchester hosted 252 international genomics experts, fostering knowledge-sharing and idea exchange. This conference advanced our understanding of developmental disorders and congenital malformations. With 83 cutting-edge presentations on the science, diagnosis, and treatment of rare conditions, it not only delivered top-notch content but also fostered a welcoming and relaxed atmosphere, facilitating discussions, promoting collaborations, and inspiring innovative approaches to enhance the well-being of patients affected by rare conditions. Participants hailed from 50 countries worldwide.

We agreed to provide expenses for building the previous conference website to Cristian Cunha. A fee of £2000 was paid. A website is important for a large meeting and also helped with marking and collation of abstracts.

5. Education

We continue to contribute to other educational initiatives through our links with the European Reference Network for Congenital Anomalies, ERN ITHACA and the European Society of Human genetics (ESHG). SB and SDH have continued to lead and participate in teaching activities in the UK and overseas. Prizes for presentations were awarded at the Manchester Dysmorphology Conference also supported by ERN ITHACA. MANTRAA supported educational activities organised by Dr Grace Vassallo for one of the commonest rare genetic condition called Neurofibromatosis 1 (NF1). Individuals with these disorders need specialist care and it's important to train GPs and other doctors to both recognise signs of these disorders and to be able to help with specialist management.

6. Collation and dissemination of reports

We continue to contribute to compilation of publications for rare conditions in the medical literature. We reiterated that we need to mention MANTRRA in the acknowledgements when this type of paper is published.

7. Future plans

- a. Organization of the ESHG Manchester Syndromology & Dysmorphology Course from 22nd – 24th October 2024
- b. Organisation of the 20th Manchester Dysmorphology Conference 16th-19th Nov 2025
- c. Continue with meeting support. Foster new liaison with NF1/NF2 group
- d. Continue management guideline work and participation in other virtual educational initiatives.

8. Accounts

Date	Item		Receipt	Expenditure
06/04/2023	Starting balance	£41,974.01		
27/11/2023	NF1 educational meeting organisation			-£312.31
Totals			0	-£312.31

BALANCE £41,661.70 as on 6th April 2024

Report compiled August 2024 by Sofia Douzgo Houge, Siddharth Banka and Jill Clayton Smith

Accounts

MANTRAA : “MANchester Teaching and Research For RAre Disease Group

Annual Report

February 2021 to 2022

1. Introduction

MANTRAA was set up as a CIO in September 2019. The main objectives of the CIO is to advance and promote the science and medical practice of Rare Disease Genomic Medicine

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2. Support rare disease meetings, specifically the Rare Disease International Meeting held in Manchester every two years
3. Support training through bursaries and scholarships
4. Aid the collation and dissemination of reports, statements and research findings

2. Changes to Trustees 2021-2022

Trustees remain the same but Sofia Douzgou has now relocated to Bergen, Norway , and Jill Clayton-Smith has retired from the NHS at the end of October 2021. Both have elected to remain as Trustees at present.

3. Work February 2021- February 2022

a) Meeting support

The instability following the COVID pandemic has meant that it has not been possible to risk planning an international Dysmorphology Meeting yet. It is deemed that the financial risk would be too great. However, things are starting to reopen and we are hopeful that a meeting can be planned for 2023.

Traditionally this has always been in the autumn. Although we discussed the possibility of moving the meeting , it is likely that we will keep to autumn, avoiding half term and other major meetings. We need to make the decision as to whether to run this as a totally face to face meeting or a hybrid online and face to face meeting. In Feb 2022 a decision was made that the meeting would be held in Manchester from 15th to 17th October 2023.

b) Education

We have not put on any specific educational events under the MANTRRA umbrella as yet, again these have been limited due to COVID risk. We have contributed to other educational initiatives

c) Training

We were expecting to welcome a number of trainees to Manchester for training in rare diseases in May 2020. Unfortunately, given the COVID restrictions this had to be cancelled and the regulations for visitors have changed somewhat. We will plan to have trainees back in Manchester and possibly Bergen as soon as travel and risks allow. Due to the fact that trainees have not been able to travel, we have not given out any travel bursaries or scholarships yet.

d) Collation and dissemination of reports

We have contributed to compilation of some reports on management of rare diseases, though have not yet published any under the MANTRRA umbrella. In particular we have been working on management guidelines for Kabuki Syndrome and PIK3CA related overgrowth syndromes where we have linked with parent support groups. One of the trustees continues to act as an editor for a Rare Disease Journal (Clinical Dysmorphology) with the honorarium for this coming into the MANTRRA funds.

4. Impact of Covid 21-22

As outlined above, we have been severely impacted by COVID, with the requirement to rearrange our conference and defer trainees. We were also due to have been involved in hosting a workshop at the European Society for Human Genetics in June 2020 and this was cancelled. We are now planning to do this as a virtual session at the next meeting in June 2021. The fact that no-one is travelling to meetings at present means that we haven't given out any travel bursaries.

5. Impact of Brexit

By virtue of the fact that the conditions MANTRRA is aligned to are rare, specialists are few and far between and dialogue and communication between experts nationally and internationally is paramount. Our network is world-wide, but we have greater interactions with our European Colleagues. Our team used to be involved in the coordination of ERN ITHACA, one of the European networks for rare diseases. Unfortunately, as we came up to leaving the EU we had to stand down as coordinators and can now no longer be members. This has some impact on our ability to work together but in fact we have well established relationships with our EU colleagues and at the present time there is no significant impact for us, although in future we may offer funding via MANTRRA for education/training /research activities as funding will not be available from the ERN.

6. Trustee/Admin Changes

One of the MANTRRA trainees, Sofia Douzgou has now moved to live and work outside the UK in Norway but remains a trustee. This means that trustee meetings and decisions now need to be virtual or by electronic communication. It has the advantage that Dr Douzgou remains within the EU and an active participant in the European Reference Networks, so maintaining our contacts.

7. Future Plans for 2022-2023 (contingent on COVID situation)

1. Reorganisation of Manchester Dysmorphology Conference (October 2023)
2. Consider other ways of trainee support if bursaries/scholarships cannot be taken advantage of at the present time
3. Continue management guideline work and participation in other virtual educational initiatives.

8. Accounts

Our income comes mainly from Honoraria for work from the Clinical Dysmorphology Journal, from other honoraria and from occasional donations. We had some initial commercial funding from an exhibitor at a meeting held in 2018.

Our main initial aim has been to accumulate a reserve fund for conferences, then look further at providing funds for other aspects of training/research. In the event we have not spent any of our funds as yet given the reasons above.

Date	Item		Receipt	Expenditure
April 2021	Opening balance	28,172.05		
January 2022	Journal honorarium		3,550	
	Closing balance	31,72205		

BALANCE £31,72205 as of 1st April 2022

Annual income 21-22 £3550

Report reviewed and finalised March 2023 by Jill Clayton-Smith

Accounts

MANTRAA : “MANchester Teaching and Research For RARe Disease Group

Annual Report

1/4/20 to 1/4/21

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2. Work since inception

a) Meeting support

Initial work of the three trustees of MANTRRA (Douzgou, Banka, Clayton-Smith) focussed on preparation for the 2020 Manchester Dysmorphology Conference , due to be held in November 2020. Various venues were researched and visited to identify suitable conference accommodation for around 220 participants, with an emphasis on encouraging participation from as many trainees as possible. Eventually, The Kimpton Hotel, Manchester was identified as the most suitable venue and a contract negotiated and signed with the hotel in early March 2020.. A search was instigated for administrative help with the conference.

By the spring of 2020, as the COVID pandemic hit , it was clear that there would be too much risk for a November 2020 conference to go ahead and after negotiation with the conference venue the date was deferred until May 2021 and then until November 2021. Currently, with the second wave of the pandemic and recent introduction of travel restrictions to the UK, a deferral of the conference until at least November 2022 was envisaged , as the aim was to have an international audience. All of these rearrangements have given rise to many discussions among the trustees. As of 1/4/21 we planned provisionally for a 2022 meeting, and were also possibly considering alternatives such as a virtual meeting. A decision was made to look into the cost of this.

b) Education

We have not run any specific educational events under the MANTRRA umbrella by April 2021, again as these were limited due to COVID risk and redeployment of doctors within the NHS to cope with the COVID pandemic. We contributed to other educational initiatives , for example an on-line course which is being developed by the European Reference Network for Congenital Malformations and Intellectual Disability.

c) Training

We were expecting to welcome a trainee from Slovenia to Manchester for training in rare diseases in May 2020. Unfortunately, given the COVID restrictions this had to be cancelled. We plan to have trainees back in Manchester as soon as travel and risks allow. Due to the fact that trainees have not been able to travel, we have not given out any travel bursaries or scholarships yet. All of the trustees did, however, contribute to training activities outside their NHS work by lecturing at various meetings. We also contributed to the setting up of the European Society of Human Genetics ESHG Young group for trainees in all aspects of genomics.

d) Collation and dissemination of reports

We contributed to compilation of some reports on management of rare diseases, though have not yet published any under the MANTRRA umbrella. In particular we have been working on management guidelines for Kabuki Syndrome and PIK3CA related overgrowth syndromes where we have linked with parent support groups. One of the trustees continues to act as an editor for a Rare Disease Journal (Clinical Dysmorphology) with the honorarium for this coming into the MANTRRA funds.

3. Impact of Covid

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6. Future Plans for 2021-2022 (contingent on COVID situation)

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2. Consider other ways of trainee support if bursaries/scholarships cannot be taken advantage of at the present time

3. Continue management guideline work and participation in other virtual educational initiatives.

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Accounts for April 2020 to April 2021

Date	Item	Amount	Receipt	Expenditure
1/4/2020	Opening Balance	21,072.05		
10/7/2020		Journal honorarium	3550.00	
29/1/2021		Journal honorarium	3550.00	
	Totals		7000.00	
1/4/2021	Closing balance	28,172.05		

BALANCE 28,172.05 as of 1st April 2021