

RARE YOUTH

illuminating RARE Talent Internship Programme
Business Partner Guide

#RAREYOUTHREVOLUTION



The Illuminating RARE Talent Internship Programme is an initiative by RARE Youth Revolution, a programme operated by NRG Collective Ltd, home of RARE Revolution Magazine.



About the Illuminating RARE Talent Internship Programme

Accessing the world of work can be a daunting process. Through our work with young people, we know that this can be amplified for our rare disease youth community. Many experience barriers to accessing meaningful work experience during education, and many go on to face significant challenges in entering the workplace and building rewarding careers in their chosen field post education.

Our youth community has told us that the lack of workplace experiences and opportunities have impacted their ability to develop skills important for employability, putting them at a disadvantage when taking their first steps into a fulfilling career and financial independence.

The Illuminating RARE Talent Intern Programme was developed for young people, by young people, via the RARE Revolution initiative as a partnership project with RARE Youth Revolution Magazine and our primary sponsor Illumina, along with a number of other project supporters such as OPEN Health and Breaking Down Barriers.

To address the current employability gap for young people with rare diseases, we are partnering with a handpicked selection of trusted industry and professional partner organisations to offer a variety of exciting workplace opportunities.

This handbook has been developed to help guide you through the process of what to expect as an organisation participating in the Illuminating RARE Talent Internship Programme.

Together we can power up young voices by illuminating a path to youth employment.

Introduction to the programme

Objectives for you – the recruiting organisation

The success of this programme depends on mutually beneficial partnerships between our professional partners and our RARE Youth interns. By participating in this programme, we anticipate that you will:

- Find dedicated, passionate, hardworking young talent from within the RARE community to fulfil your internship positions
- Recognise the fresh skills and perspectives that can be brought into your organisation by talented young people with rare diseases
- Discover that employees with disabilities or health conditions are as productive and valuable members of the workforce as those without.
- Develop the skills, techniques, and confidence to hire and develop employees with rare diseases and other disabilities within your organisation.

We hope this process will empower your organisation to make more diverse hires in the future – by encouraging those with rare diseases or other disabilities to apply, you are widening the number of high-quality applications available to fulfil your employment needs, as well as improving health diversity in your staff and reflecting the diversity of your customer base and community.

Objectives for the intern

The primary objectives for our youth participants are to enable them to:

- Gain experience first-hand what it is like to work in a professional environment
- Develop valuable workplace skills that will enable them to take their next steps along their career path and enhance their employability.
- Form meaningful professional connections with potential mentors, referees, and colleagues.

The Illuminating RARE Talent Programme

Step 1: Joining the programme

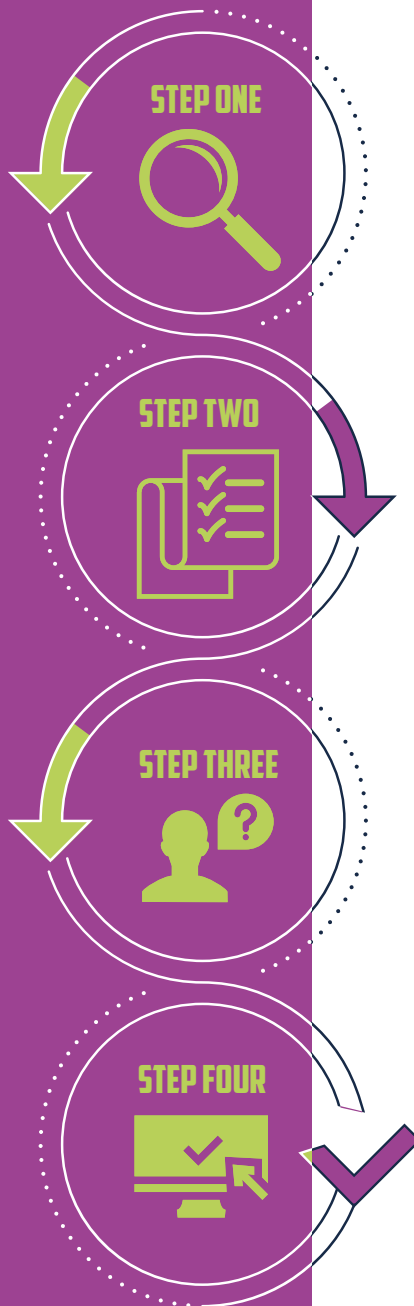
- **Register your interest:** The first step for you as a potential industry partner is to register your interest with us, which can be done via our industry programme coordinator and business development associate, David Rose: drose@rarerevolutionmagazine.com
- **Book a discovery call:** Once your interest is noted, David will arrange a call with you and your team to explain more about the internship programme and how it works, and to learn more about your organisation and the type of placements you might be able to offer.
- **Partner registration:** Once you are happy that this is an initiative that you are keen to be involved with you will be asked to sign our Memorandum of Partnership (Appendix A) to confirm your commitment to this programme. At this point we will ask you to complete a job description proforma for the internship role on offer (Appendix B). You may have more than one internship placement available, in which event you can complete one form per position.
- **Advertise your vacancy:** Once our team have reviewed your internship placement details, we will add this to our online job board which can be found at: www.rareyouthrevolution.com/internship. Vacancies will also be shared about our RARE Youth Revolution social media channels and by e-newsletter.

Step 2: Finding your candidate

- **Application process:** Applicants will apply through our online portal where they can submit their CV and supporting information. This process will be managed by us on your behalf. (See Youth Onboarding Document for full youth application process)
- **Application reviewed:** Once we receive applications for your internship post these will be internally verified by our team and checked against the eligibility criteria. Once verified, all applicants' details will be shared with your team for review, and a review board comprised of delegated members of your team, and ours will convene to review the applicants. A selection will be made of those candidates you wish to progress to interview stage. We will notify those applicants who are not selected to progress to interview on your behalf.
- **Interview:** An interview will be coordinated between yourselves and the suitable candidates, and we recommend our RYR coordinator is also present. Interviews can be in person or virtually at the discretion of the recruiting organisation and applicant.
- We will notify unsuccessful candidates on your behalf and feedback any commentary where appropriate. We will also notify the successful candidate so that they can confirm their acceptance or otherwise, and appropriate onboarding can be carried out.

Step 3: Onboarding your new candidate

- **Job offer and acceptance:** Once you have chosen your successful candidate, and they have accepted your offer, it is time to get ready for them starting their placement. This means communicating effectively with your new intern regarding their start date, time, location and full details about their role and responsibility. Please make sure that you provide them with the relevant induction information as soon as possible. You should also ensure that you discuss with your new intern any reasonable adjustments that they require to do their work. Remember, it is your duty as an employer to remove, reduce, or prevent any barriers that could impinge on a person doing their job. Further details on implementing reasonable adjustments and support with negotiating any costs is available in the section on Reasonable Adjustments for Workers with Disabilities or Health Conditions.



- **Induction and training:** If the intern is required to attend any induction or training in advance of starting their role, please make sure they are aware and prepared. If this takes place at an alternative site to their normal place of work, you should check in advance that their reasonable adjustments can still be accommodated. You should also ensure that they are provided with any relevant company policies, guidance, and details to allow them to thrive in their role.

Please see below for more specific guidance under the section.

Step 4: When the placement comes to an end

- **Exit interview and feedback:** At the end of your placement interns should be offered an exit interview so that you can both feedback on the achievements, process, and ways to improve the experience for the future.
- **References:** We hope that you will feel able to provide your intern with a written reference to aid them in their future chosen careers, which reflects their time with you. However, if you are not able to do this, please do let us and your intern know in the exit interview.
- **Share your experiences:** In order to help others to benefit from your experiences we will encourage you to share your experience with our wider rare youth community, via social media campaigns and blogs. We might also ask you to provide a testimonial for promotional purposes or ask you to speak to other industry partners considering joining the initiative.

Your responsibilities and obligations as an internship provider

In order that both you and your new intern get the best from this experience it is important that you onboard your intern and provide them with adequate information and support in pursuit of their role, so that they can thrive within your organisation.

This includes your responsibility to make sure that they are familiar with company policy, procedures, and culture, whether verbal, written, or implied. It also includes your duty as an employer to make reasonable adjustments for any employees with a disability or health condition to reduce, remove, or prevent barriers to doing their job.

Your legal obligations

Reasonable Adjustments for UK internship providers

UK law states that “employers must make reasonable adjustments to make sure workers with disabilities, or physical or mental health conditions, are not substantially disadvantaged when doing their jobs. This applies to all workers, including trainees, apprentices, contract workers and business partners.” Reasonable adjustments are usually very straightforward and inexpensive to implement, and there is plenty of support available to guide you if you are unsure of what to do. Some key documents are listed below that may help you consider what solutions can be provided to support interns within your workplace.

- A definition of what is classed as a disability is available here: www.gov.uk/definition-of-disability-under-equality-act-2010
- Basic guidance on what reasonable adjustments may look like is available at: www.gov.uk/reasonable-adjustments-for-disabled-workers
- The Equality and Human Rights Commission has additional guidance on what types of reasonable adjustments are commonly encountered and how to integrate them into your workplace: www.equalityhumanrights.com/en/multipage-guide/employment-workplace-adjustments

Key to supporting your young person with a rare disease is to communicate with them, ask what adjustments are needed, and be willing to find solutions that will enable them to work successfully with you.



Non-discrimination in the workplace

It is unlawful to discriminate against another in the workplace based on their race, colour, religion, gender, sexual orientation, national origin, disability, or age.

By participating in this programme as a partner organisation you acknowledge that you will ensure that you follow all statutory non-discrimination laws upon which you are bound by. Furthermore, that you will follow best practice in being an employer who actively seeks to negate against discrimination in the workplace.

This shall include compliance with all accessibility law and statutory obligations in regard both short and long-term sick leave.

It is your obligation to familiarise interns with your corporate policy with regard to the above.

Confidentiality and non-disclosure

It is your responsibility to ensure that interns are familiar with any confidentiality and/or non-disclosure policies within your organisation to ensure they know how to process commercially sensitive, or manage personally confidential materials, and that they know how to operate within any relevant internal policies and wider regulatory guidance with this regard. Please ensure your intern is provided with any relevant training and a point of contact if they are unsure.

GDPR and data protection

It is your responsibility to ensure that your organisation robustly follows laws in relation to GDPR and data protection and that you have up to date procedures and supporting processes in place to reflect this. Furthermore, you are responsible to ensure that any intern under your care is aware of these important obligations and how to satisfy them in pursuit of their own role.

Safeguarding

Safeguarding refers your obligations, as the recruiting organisations, to keep interns under your care safe and protected during their time within your organisation. The obligations and responsibilities with regard to this will differ depending on the nature of the role, so please ensure that interns are made aware of your Safeguarding Policy on joining.

Communication, etiquette, and conduct

Good communication is vital for the success of any placement. As such interns should be made aware of your company expectations regarding the following:

- Company structure and communication channels
- In person communication
- Communication via virtual platforms such as Zoom/Teams etc
- Across social media channels
- In writing via email or mobile chat systems

Company structure and line of communication e.g., Line manager, human resources

You should ensure that the intern understands your company structure and any reporting or management lines of communication so that they can be respectful of these in their day-to-day duties, but also in the event of them needing to raise an enquiry and communicate with other departments, for example human resources, etc.

Make sure that candidates are familiar with the following:

- Who is my point of contact/line manager?
- Who do I raise any issues with?
- Who is the designated first aider (where appropriate)?
- How can I keep in touch with RARE Youth Revolution?

You are required as a participating organisation to keep in touch with your intern coordinator at RARE Youth Revolution, and we encourage you to share your intern's progress with us. Should you need any advice on how to deal with an emerging issue with your intern, then RARE Youth Revolution will be on hand to help support you.

Likewise, if you need advice on any matter relating to the programme, support is always on hand. You can keep in touch with RARE Youth Revolution by emailing your RARE Youth coordinator, at hello@rareyouthrevolution.com

Workplace etiquette and conduct

In-person and email communications

It is your responsibility to ensure that interns know your expectation with regards to use of appropriate language and conduct at via in-person and email communications.

This may mean:

- Informing them of, and demonstrating to them, best practice in in-person and email communications, such as avoiding any slang, jargon, or colloquial terms, specifying appropriate greetings, and guiding them through professional writing or speaking conventions relevant to the role
- Ensuring that your intern is familiar with the internal protocol with regards to in-person and email appointments, meeting scheduling, and communications
- Summarising or demonstrating how to conduct themselves in a professional manner conducive to representing your organisation whether internally or externally

Social media usage guidelines

It is your responsibility to ensure that your intern understands any expectations with regard to phone and social media usage during work hours. You should also ensure that they are familiar with any company policy regarding representing your brand via social media and any public facing channels within or outside working hours.

Meeting commitments and obligations

Attending meetings in person or virtually may be a new experience for your youth intern. Please take the time to outline your company etiquette with regards to meetings. For example, dress code, use of virtual backgrounds, time keeping, etc.

Training

It may be necessary for internal or external training to be carried out to support your intern in their role. It is your responsibility to ensure that candidates are aware of their obligations for training and are prepared to engage in such training.

It is also your responsibility to ensure that if your intern needs any reasonable adjustments made to complete the training, especially if this is to be done at an alternative location or is outsourced to an external provider, that these are met in a timely and effective manner.



Supporting your interns in their role

It is of paramount importance to us that you, the recruiting organisation, and ourselves at Rare Youth Revolution can collaborate to create a work environment that will allow interns to thrive in their role and maximise the opportunity for their career development. As such, here are some ways that we can work together to realise that vision.

Discussing needs and ensuring necessary support measures are in place

Before the placement commences, successful candidates will be given the opportunity to share their individual needs with the RARE Youth team so that they can ensure that these are adequately catered for within any future role.

To make sure that this is as seamless as possible we ask interns to be clear and honest about any limits they may have, whether these are limits on work due to physical health, or because of their mental health. Identifying these limitations help us to work with you as the recruiting organisation to ensure we find the right role for individuals and can ensure that you are able to meet their need(s) adequately and consistently.

It is also important that the intern feels comfortable discussing any new emerging issues with you, in recognition that rare diseases can be dynamic, and their needs may change over time.

Managing expectations

We all know that sometimes things happen, and an employee may not be able to do their job to the best of their ability. This is especially true when working with complex health needs. As such it is important that your intern knows how to communicate this effectively to you as soon as possible and keep dialogue open with you.

- **What to do if they cannot attend due to ill health:** If due to health needs they are unable to attend work or fulfil the obligation of the role fully, ensure your intern is aware that they are required to notify you as their recruiting organisation/line manager at the earliest opportunity, and which methods of communication are preferred.
- **What to do if they cannot attend due to planned medical appointment:** If your intern needs time off to attend planned or urgent medical appointments, ensure they know that they should notify you as their recruiting organisation/line manager in advance to that your can plan for their absence.
- We recommend that the intern also notifies their intern coordinator so that we are also aware.

It is your responsibility to ensure that interns are aware of this process and able to communicate this effectively through the correct company procedures and channels.



Managing workload based on ability

We encourage companies to maintain regular dialogue with interns to ensure they are coping with the workload assigned, alongside their health needs, and that adjustments are made when required.

Personal assistants

Many individuals within the rare disease community require the support of a personal assistant to provide valuable assistance to them in their day-to-day lives. The following provides some guidance on the use of PAs in the workplace.

- **Appropriate use of the personal assistant:** If an intern requires a personal assistant, it will be important that they are not misused during the intern's employment. The personal assistant will be there to facilitate the intern doing their job. They should not be performing any of additional duties or used as an extra employee, i.e. performing tasks that are not allocated to the intern. Applicants should declare in their initial application and or interview if they anticipate a PA being present during their working hours.
- **Non-disclosure for the PA:** Similarly to the applicant, personal assistants will need to know what information can and cannot be shared to ensure that no confidential information is leaked. As such the PA should also be asked to sign any relevant non-disclosure agreements. PAs should also be acquainted with your GDPR and social media policies.

Mental health support

New experiences and situations can feel overwhelming so taking care of your intern's mental well-being is essential. Please ensure that your intern is aware of any wellbeing policies within your organisation and any internal channels of support that are available to them. We have also signposted them to the following resources within their own onboarding guide.

- www.mind.org.uk/information-support
- <https://hubofhope.co.uk>
- www.nhs.uk/mental-health
- www.mind.org.uk/information-support
- <https://hubofhope.co.uk>
- www.nhs.uk/mental-health/advice-for-life-situations-and-events/mental-health-support-if-you-are-gay-lesbian-bisexual-lgbtq
- www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/lgbtplus-mental-health
- www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/black-asian-and-minority-ethnic-mental-health
- https://helpline.barnardos.org.uk/?gclid=Cj0KCQjwm9yJBhDTARIsABK1cGb8xpSNJWZIVRZY567_-b417Q4egHE8jeRBpzX2MtFWrEiNeGc5gAwaAtleEALw_wcB

Contacting RYR

If you or the intern need further support on this, or any other matter, you/they can contact the RARE Youth Revolution coordinator (hello@rareyouthrevolution.com) so that they can provide further guidance.

FAQs

What do I do if the placement isn't working, or the candidate is unsuitable?

We know that sometimes placements don't work out and this can be for a number of reasons. We recommend that this should be discussed with the candidate in the first instance to see if matters can be resolved. If the placement is not suitable to progress, please reach out to a member of our team at the earliest opportunity so that this can be discussed, and a plan of action agreed.

Can I terminate the placement early?

Refer above.

Can we extend the placement?

Yes, absolutely. By mutual agreement with the candidate organisations can seek to extend the placement if it is mutually beneficial to both parties. This may be an appropriate time to review terms. For example, should this now be a paid opportunity or are the working hours suitable moving forward.

How long should internship placements be?

Placements can range from week-long voluntary work experiences to 12 month paid internships, and everything in between. Our team will discuss your requirements during onboarding to arrive at the right duration and term for your organisation.

What rates of pay are expected for paid placements?

Where placements are paid opportunities, we would ask that organisations consider carefully fair and appropriate remuneration, and this should not be less than any regional statutory minimum or living wage. In line with good practice we expect as a minimum, that all placements over a six week duration should be paid internships.

Are the potential interns of mixed levels of degree/education and employment experience?

Due to the range of opportunities offered candidates will have varying backgrounds in terms of education. We encourage organisations to be openminded and look at the candidate and their life experience as a whole and not just academic merits. This makes for a richer experience. If there are minimum educational requirements for the role these should be advised within the Intern Requirements Proforma.

Do the companies choose the intern? Or is it RARE Revolution?

All applicants will be submitted to you for consideration, and a panel comprising your delegated team members and a representative from our team will review these collectively.

What happens at the end of the Internship?

Refer to Step 4 (see page 5)

Will the applicants be UK residents?

This is an international programme. When defining your requirements, you will be able to select if you are open to international candidates or if geographic criteria apply. You should consider if this is home working or office based, and the impact differing time zone may have on operational effectiveness and management of the candidate.

What age range is considered for this youth programme?

The programme is open to individuals aged 16 to 25 years old.

Are all the companies involved directly linked to the rare disease industry?

In short no. There is no requirement for the partner organisation to be operating in the field of rare disease. We hope to offer a wide range of opportunities to our youth community both within and outside of this field.

Is it an all-year-round recruitment drive?

Yes, this is a rolling programme. We acknowledge that no two companies are the same therefore by operating on a rolling basis we can meet the needs of organisations and candidates more fully.

Do all the young people have a rare condition specifically?

The premise of this programme is to up-level young people for whom their career opportunities might otherwise be detrimentally impacted by virtue of their rare and complex health needs.

Are the roles offered going to be office based, work from home or a hybrid?

We welcome opportunities in both office based and home working. Organisations that require an office-based candidate should think about any required reasonable adjustments along with contingency plans in the event of a region lockdown or period of restrictions resulting from the COVID-19 pandemic.

How much contact will RARE Revolution have during the duration of the role?

Ultimately the partner organisation is responsible for the day-to-day management and support on the candidate once they are in post. However, the team at RARE will be on hand to talk to throughout the placement and will carry our regular contact reviews with both parties during the placement.

Can we take on more than one intern at the same time?

Yes absolutely. We welcome companies who can support more than one candidate, and this can be discussed on your onboarding call.



www.rareyouthrevolution.com/internship
hello@rareyouthrevolution.com