

RARE YOUTH

Illuminating RARE Talent Internship Programme
Intern 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 difficulties accessing meaningful work experience can be amplified for our rare disease youth community. Others like you, who live with one or more rare disease(s), have told us of their struggles to obtain work placements during education, with ongoing impact on their ability to develop employability skills that would set them up for fulfilling future careers and financial independence post-education. With this in mind, we want to help you to gain vital hands-on experience of work placements that will help you overcome some of the challenges involved in entering the workplace and building a rewarding career in your chosen field post education.

The Illuminating RARE Talent Internship Programme was developed for young people, and by young people, via the RARE Youth 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 this current gap in available work placements for those living with rare diseases, we have partnered with a handpicked selection of trusted industry and professional organisations who are offering a variety of exciting workplace opportunities for people like you.

The following handbook will help guide you through the process of selecting, applying for and participating in your internship through the Illuminating RARE Talent Internship Programme.

Together, we are powering up young voices and illuminating your path to youth employment. You have officially made the first step into your future career!

Introduction to the programme

Objectives for you, the intern

- The primary objective of this internship placement is for you to experience first-hand what it is like to participate in a professional working environment and to gain valuable workplace skills that will help set you up for the next steps on your career journey by enhancing your employability
- Doing an internship is also a valuable opportunity for you to form meaningful professional connections with people who may be able to provide you with information, opportunities and references that will help you to identify and seek out your perfect career path

Objectives for the recruiting organisations

Part of the success of this programme depends on you, the intern, having a positive workplace experience, but we also want to provide our professional partners with positive experiences of working with young people with rare diseases. We want our partners, through collaborating with you and with us, to:

- Recognise the value that employing young people with rare diseases can bring to their organisation
- Help change industry perspectives of the benefits and challenges of employing young people with rare diseases, to empower organisations to make such hires in the future, improving health diversity in their staff
- Seek out dedicated, passionate, hardworking young talent from within the RARE community and continue to offer them work placements and career opportunities

Applying for an internship position

We want to make applying for an internship position through the programme as straightforward and easy to navigate as possible. Our dedicated RARE Youth Coordinator will be on hand throughout the process, helping to support and guide you as needed.

Step 1: Find your dream job

Check out our RARE intern notice board (www.rareyouthrevolution.com/internship) to view all current opportunities available and learn more about the various roles and participating organisations

New internship opportunities will be regularly posted on our RARE intern notice board. Here you will also find the full details for each role and how to apply. Information will include:

- The description of the role
- The mandatory and desirable criteria required to apply for the position
- The length of time the internship is offered for, e.g. 2 weeks, 1 month, 3 months, etc.
- Details of any salary or whether the role is unpaid
- Whether it is a homeworking or office-based position
- If there are any non-negotiable constraints within the role, such the location (e.g. an office-based position in London) or a requirement to travel as part of the role

Step 2: Check the criteria

Once you have found your dream internship position, you should check any mandatory criteria to make sure that you are eligible for the chosen role.

This may include:

- Minimum age
- Location
- Ability to travel
- Existing knowledge or skills
- If relevant, timings in relation to your educational commitments

If you do not meet some or all of the desirable criteria, you may still be suitable for the role. Please check with your RARE Youth Coordinator if you are unsure.

Step 3: Ask questions

Questions about the role you are keen to apply for are perfectly normal. Make sure you re-read all the available information to make sure you haven't missed anything that would help you answer your own question.

If you still need more information, we're happy to hear from you! Please contact your RARE Youth Coordinator at: hello@rareyouthrevolution.com.

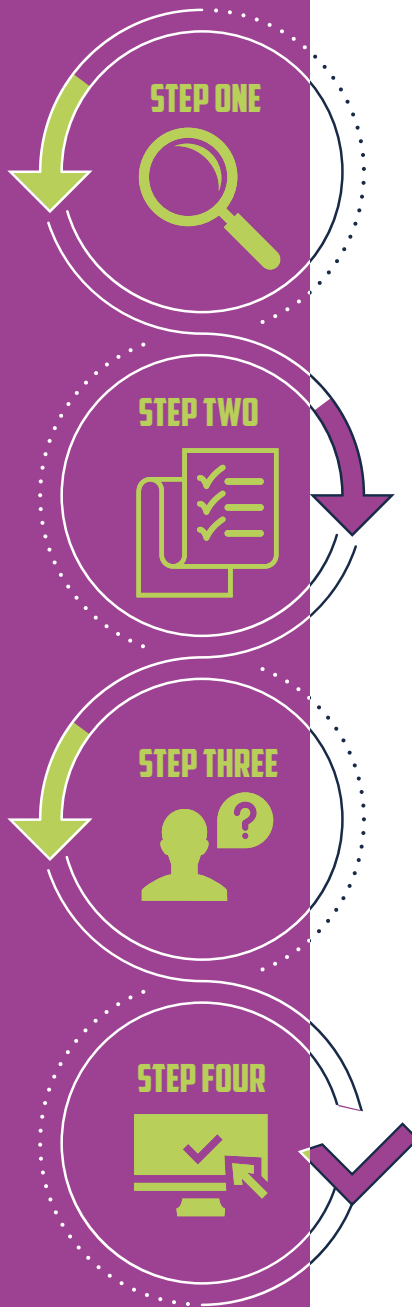
Make sure you tell us which role you're interested in applying for and that you give us at least 3 working days before the closing date to answer your query, as we may need to consult with our partner organisations.

Step 4: Time to apply

Once you have checked the criteria and had any questions answered, you are ready to apply!

Check out our top tips for writing and editing your application to help it stand out from the crowd

See our top tips for making your application stand out



8 top tips for writing

1. Make sure you check the **mandatory eligibility criteria** before you apply. You want to **specifically address these criteria** when you are writing your application statement. Your potential future employer needs to know how and **why you fit the role** they've advertised.
2. Research your chosen role. What are the **company's vision, values and ethics**? Showing interest in the wider organisation and specifying what has drawn you to this company and this role helps show your interest and commitment to the position.
3. Don't be afraid to **write in the first person** and **let your personality shine**. This is **your** application, and your prospective employer needs to know what **you** can bring to their organisation. Even when you are discussing teamwork skills, try to **pick out what you bring to a group** and how you help a team work well together.
4. Don't be afraid to acknowledge your disease. Only share what you are comfortable sharing and what is relevant to the application, but showing knowledge of RARE Youth Revolution and the value of hiring employees from the RARE Youth community may be helpful.
5. Be **clear and concise**. Employers often have lots of applications to read so make their job as simple as possible by giving only the most **relevant information**. You want to give them enough so that they can see what you would contribute to the role and how you fit the criteria, without overdoing it. Think short paragraphs rather than one or two sentences, or an essay!
6. Sell your strong points. When trying to decide **what information is essential** to share, **give examples** from your education and/or prior work experience that **illustrate your strengths and skills** in relation to the mandatory criteria.
7. If you don't meet some of the desirable criteria, that's all right. It is often sensible to acknowledge this briefly in your application and **state your willingness to learn or undertake training** to meet these while in your role.
8. The ideal length of a **personal statement is one side of A4** divided into 3–6 paragraphs. Similarly, a **CV should fit onto one page**. Your entire application should ideally fit on **two sides of A4 in total**.

4 top tips for editing

1. **Re-read** your application to **check for accuracy and typos** before you hit submit.
2. Ask **someone else to review** your application before you submit. Get them to look for **clarity of communication**, any outstanding **spelling and grammar mistakes**, and even **any additional relevant skills** of yours that you might have missed out!
3. Get your application in on time. Check both the **date and time** the application is due and make sure it is in **before or on the deadline**.
4. Downloading or using Word-based **CV templates** may help you organise your information. If you want to create your own layout, **keep the design simple**, use a **standard font** such as Times New Roman or Arial, use **bold for headers**, and stick to **black and white**. Clear and readable layouts with strong content have the most impact.

Now you're ready to go!

Please visit www.rareyouthrevolution.com/internship to complete your application and then hit SUBMIT.

The interview process

Step 1: The review process

Once you have submitted your application, it will be reviewed by our internal team for completeness and then passed to the recruiting organisation for consideration. Once all applications have been considered, the review panel will select candidates who have made it through to the interview stage, and you will be notified of your status. How long this takes may vary depending on the role and the number of applications, but your RARE Youth Coordinator will keep you updated on your application's progress.

Step 2: The interview

Successful applications: If you are selected to be interviewed for your chosen position, you will be offered a mutually convenient time for this to take place. Interviews may happen virtually or in person, depending on the position being applied for. It is your responsibility to make sure that you come to this interview prepared and on time. This is your time to shine, so make the most of your chance to secure that dream internship. See overleaf for our top tips on how to make your interview a success.

Unsuccessful applications: If your application is unsuccessful and you are not invited for an interview, your RARE Youth Coordinator will contact you to provide feedback on your application and discuss your next steps in finding a work placement, such as pointing you towards other suitable potential roles. Please be aware that there will be no route to appeal if you are not selected for interview. The decision of the recruiting organisation is final.

Step 3: Receiving your job offer

Once all candidates have been interviewed, the review panel will select their chosen intern and notify us of the successful applicant. We will then contact all applicants to let them know the outcome of their application.

- **Successful interview:** If you have been successful and the company wishes to hire you as their intern, you will be issued with a formal offer letter and contract, which will set out the terms and conditions of your internship. All that remains now is for you to confirm your acceptance and agree a start date!
- **Unsuccessful interview:** If you have not been chosen for an internship this time, don't be discouraged — the competition for places is strong, so this isn't a reflection on your value. We encourage you to keep looking at the RARE Intern Notice Board and keep searching for the opportunity you have been waiting for



10 top tips to make your interview a success

1. Dress for success. **Smart, clean, tidy attire** helps make a good first impression. Wearing something in your favourite colour (e.g. a shirt/top, tie or even hairgrip) can help you feel like yourself if formal dress isn't something you often wear, and it's okay to show a bit of your personality too, as long as you appear professional.
2. **Arrive on time**. Allow time for transport to be late and to find the building and the room if you are travelling, or time for computer and connection issues if meeting virtually. Punctuality is important.
3. For virtual interviews, make sure you **have a suitable background** set up when your camera is on. To maintain a professional appearance and for safety reasons, it's best not to show the inside of your home or anything that might reveal your address. **Your RARE Youth Coordinator will make an optional virtual background available** to you ahead of your interview should you wish to use it. Try to **minimise any background noise too**.
4. Do your **background research** on the company you want to work for. Even if you did this for your application, it is important to refresh your memory and think about how you, in your chosen role, can contribute to the company culture, vision and values. Employers are more likely to be impressed if you can **show you are already interested** in what they do and how you will fit in.
5. **Research common interview questions** to prepare yourself for the sort of things that you might be asked. Every interview is different, and you may not be asked the specific questions you've researched, but knowing what kinds of things often appear will help you think about how to talk about your skills and experience in different scenarios. Try not to get anxious about possible 'trick' questions — these are rarely used by reputable companies and, even if you do get one, it's likely to be asked to show how you think about an unexpected problem, so **stay calm** and take your time with your answer.
6. Make a **list of examples** of situations and scenarios in your educational or previous work experience that you didn't use in your application to use in your interview to show off your skills and knowledge; you want to build on what you've said before, not restate what you've already said. Think particularly about **how your skills might help the company**. If you have a passion for a certain area of work, let them know and apply it to their company; for example, if you love social media, explain how you could make theirs take off, and show your passion.
7. **Listen carefully** to the questions that are asked, make sure you know what they're looking for, and don't rush. Take a deep breath, give yourself a moment to think, and then reply.
8. Be prepared to **ask questions** too. You will often be given an opportunity at the end of an interview to ask questions of your interviewers so you can make sure the company is the right fit for you. There are examples of sensible questions to ask online, so do a little research as well as thinking about anything outstanding that you would like to know about what you would be expected to do and how you might best succeed if you get the position.
9. **Be yourself and believe in yourself!** You are your best asset, **sell your strong points**, and don't be afraid to admit your weaknesses, but let them know you are **willing to learn** and will always **ask for help** if you don't know the answer!

What to expect: starting your new internship

Step 1: Preparing for the big day

Ahead of your start date, make sure that you have all the information you need to make your first day a great one! Some key things to think about are:

- Do you know where your new office is and how to get there?
- What dates and days you are expected to work?
- What times do you start and finish, and do you have set breaks?
- Do you know what the dress code is?
- Who is your line manager and/or mentor? Do you have their names and contact information so that you can ask for help if you need to?
- Does your new employer know about any reasonable adjustments related to any of your health conditions that they need to make to help you do your job, and are these in place?
- If you're working virtually, do you have the right technology and know how to use it?
- Do you need to bring any equipment, money for food and drink, or a packed lunch? A note-taking device is always essential!

Step 2: Your first day

- Arrive on time and dressed appropriately for your role
- Report to reception or your named contact as advised by your employer
- Bring and use a note-taking device, e.g. a notebook and pen, or a device with a notetaking or dictation app, so that you can jot down things you are told during your induction. You might not remember everything, so it helps to have notes to look at afterwards
- Starting a new job can be overwhelming at first, so stay calm, get to know people, and try to enjoy yourself. Remember, the company has chosen you for this internship. You are wanted and valued, and your new team is here to support you

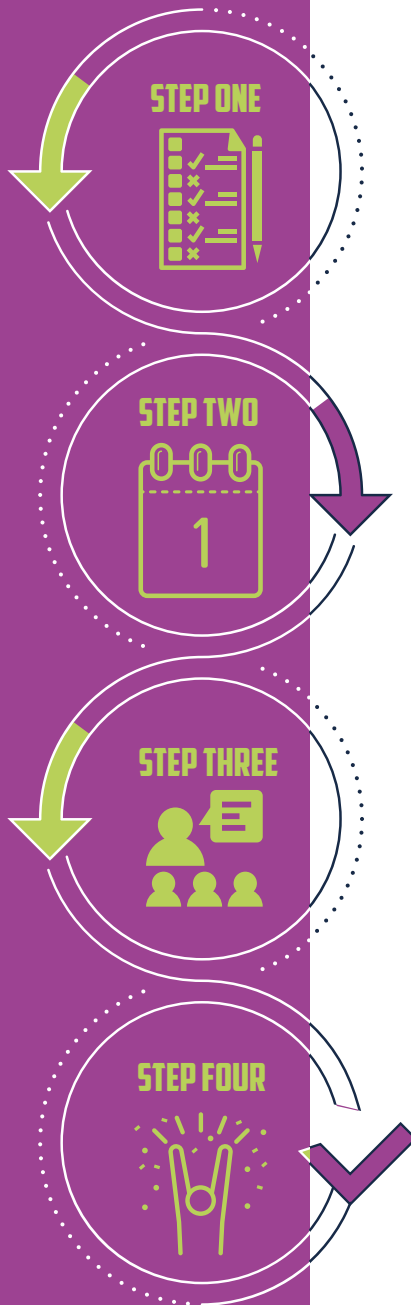
Step 3: Induction

Your first day and week will involve a staff induction and orientation to meet key team members, visit important locations and understand how your role fits into the wider organisational structure and activities. This will be your time to find out more about what your job will look like on a day-to-day basis and the company's expectations of you, so keep on asking questions!

Step 4: Enjoy your new job!

Whether it is a short-term voluntary internship or a longer-term paid placement, what you get out of the experience is dependent on what you put in. These internships are highly valued workplace opportunities, so we encourage you to make the most of it and immerse yourself fully into the experience

This is your time to show the world what you are made of and illuminate your own personal RARE talent!



8 top tips for RARE working as a young person

1. **Be prepared** for your work. Make sure you **have your tasks clear**, either on paper or in your head, so you don't get overwhelmed if there are lots of different things going on at once. Write a list or have a weekly planner so that you know **what you are doing each day**. Speak to your line manager or mentor if you are not sure **which tasks are highest priority** and should be done first.
2. Give as much **notice to your employer** as possible when **requesting time off** for appointments. If your condition means you have regular check-ups or can sometimes feel too unwell to work without warning, make sure they are aware from day one.
3. **Be honest** about the things you need to be the best you! If you need **special software or equipment** to flourish in your role and have your needs met, ask for it!
4. **Be brave**, starting a new role can be scary, especially if you have a rare condition or disability. Sometimes managing everyday life can be tricky, so add a new job into the mix and it can become a lot! Make sure you **look after yourself** and set yourself up to succeed.
5. **Ask for help**. If you are stuck or struggling with a task, don't waste your time worrying or trying to do it without really understanding the goal. **Ask for advice and guidance** from your line manager, mentor or a colleague if you need it.
6. **Take a break**. Working from home is different to working in an office; you don't get the little breaks that come naturally — going to the coffee machine or chatting to someone across the room doesn't happen. So make sure you create your own breaks to get away from the screen glare and get some head space.
7. **Be confident**. You might think everyone else has it figured out around you and that you don't — but you do! No single person is 100% confident in their role all the time. Everyone has bad days and things that make them nervous, so just trust that you can do this and that you can ask for help with things that are challenging or unfamiliar.
8. **Show your passion**. If you care about a certain topic or way of working, show this through your work. Put **maximum effort** into your tasks (this may look different every day!). Be creative and **put your ideas forward** when asked. **Don't be afraid of constructive criticism** — it is good business and will help you to develop your professional talents.

What to expect: when your internship comes to an end



Step 1: Exit interview and feedback

When your internship comes to an end, you will have an exit interview with your line manager or a representative from your recruiting organisation. This will be an opportunity for them to give you feedback on your time with them, and likewise for you to share how the experience has been for you.

Subject to the length of your internship, you may also have interim feedback sessions. At the end of all internships, as well as periodically throughout your placement, you and your recruiting organisation will also be offered opportunities from the RARE Youth Coordinator to feed back on both your experience of your role and the RARE Youth Revolution internship programme as a whole. This is invaluable in helping us make sure all parties get the most out of the experience and in shaping the programme both now and in the future.

We really appreciate your feedback and encourage you to participate fully in this process. In exchange for your collaboration, we will keep you up to date on the evolution of the internship programme via an alumni newsletter and a mailing list if you would like to hear about our future work. There will also be opportunities to build up your CV by participating in our voluntary mentoring programme (for more information, see step 3 below).

Step 2: References and looking to the future

Your recruiting organisation will be offered the opportunity to provide you with a reference based on your time with them, which will be useful in your search for future employment. This may be a document that you need to retain yourself or a verbal agreement to be a referee who can be contacted to provide a tailored reference for you in future job applications.

Make sure you check before you leave what sort of reference your organisation is willing to offer you and, if it is an offer to be a referee in the future, who to contact to request it from when you next submit a job application. Remember: it is good manners to contact your referees each time you apply for a new job and to give them at least 7 working days to create one for you.

This might also be a good time to discuss any future opportunities or the potential for additional work within the recruiting organisations. Even if your organisation does not have any availability now, see if they have any ways in which you can keep in touch with your colleagues and mentors.

Step 3: Share your experience

In order to help other young people with rare diseases to become interns, we'd love you to share your experience with our wider RARE Youth community via social media campaigns and blogs. We might also ask you to consider being a mentor for future internship cohorts so that you can help guide and support them in optimising their experience, while also gaining valuable mentoring skills for yourself. While we are currently unable to provide payment having published content on social media and mentoring experience are useful additions to your CV and voluntary work portfolio. This may support your future job applications, and we will continue to provide advice and guidance if you want to become a mentor.

Your responsibilities and obligations

Now that you have a good understanding of the application and job matching process, here is some further guidance on your responsibilities and obligations to help you feel prepared and get the most out of your internship placement.

Communication is key

Good communication is vital to make a good impression, and we expect candidates to exercise timely and professional communication throughout all stages of the process, whether that be with the team here at RARE Youth Revolution, your recruiting organisation or third parties you come into contact with. This includes the following:

- In-person communication
- Communication via virtual platforms, such as Zoom/Teams, etc.
- Posts on social media channels
- Written emails or online chat systems

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

It is important that you take the time to get to know the company structure and any reporting or management chains of communication so that you can be respectful of these in your day-to-day duties. It is also important in the event of you needing to raise an enquiry and communicate with other departments, for example, if seeking help from human resources, etc.

Make sure you are familiar with the following:

- Who is your point of contact/line manager?
- Who should you raise any issues with?
- Who is the designated first aider (where appropriate)?
- Who is your RARE Youth Coordinator?

Contact with RARE Youth Revolution

You are required to keep in touch with your RARE Youth Coordinator, and we encourage you to share the highs and lows of the experience with them. Should you need any advice on how to deal with any emerging issues within your role, that have not been satisfactorily addressed via the above chain of command, then your team at 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.

Contact RARE Youth Revolution immediately if...

If you are uncomfortable discussing an issue with your employer

If you are no longer comfortable continuing with your placement

If you feel like your employer is not catering to your needs

If you feel unsafe on your placement

You can keep in touch with the RARE Youth Revolution team by emailing hello@rareyouthrevolutionmagazine.com through the RARE Youth Revolution social media pages.

Confidentiality and non-disclosure

When you join a company, you may become privy to sensitive information about the organisation and your job. This may be commercially sensitive or personally confidential, and it is your responsibility to ensure that you respect the privacy of your organisation. All companies will have relevant internal policies and wider regulatory guidance to tell you how to behave and what not to do with confidential information. You should take the time to familiarise yourself with the company policies and make sure you adhere to them at all times during your placement and after leaving the company. If you have any questions these should be directed to your line manager for clarity.

Should you have any concerns about the legalities of what you are being asked to keep confidential or feel that anything inappropriate is going on, please contact your RARE Youth Coordinator.

GDPR and data protection (statement to be added)

In pursuit of your role, you will be obliged to comply with all statutory regulations relating to GDPR and data protection. Please ensure that your placement organisation provides you with all procedures and supporting policies so that you can familiarise yourself with these requirements.

Email etiquette

When emailing colleagues within your recruiting organisation and any contacts you may have to communicate with outside the company, you will need to use the appropriate language and conduct at all times. Each company will have their own internal protocol with regard to email conduct, which it is important that you read and follow.

However, a basic guide is as follows:

- Address your emails formally, e.g. 'Dear [named contact]'
- Avoid any slang, rude or colloquial words, and emotions
- Be specific about who you are, why you are contacting the person, and what you would like them to do and in what time frame
- Say 'please' and 'thank you'
- Sign off using appropriate salutations, such as 'Best wishes', 'With regards' or 'Yours sincerely'

Colleagues may allow you to be more informal, but do not assume. Follow their lead in how to address and communicate with them.

Social media usage guidelines

Your employer will have guidelines set out on the use of your phone and social media during working hours. These must be adhered to, to ensure that you are not being distracted or wasting time during your working hours.

For many organisations, social media channels are the public face of the company. Whether you are asked to promote the company via their own channels or whether you are simply talking about your job on your own accounts, remember that you are seen to be representing the recruiting organisation and its associates at all times online. Conduct yourself according to the confidentiality policies and make sure you would be happy for your employer to read anything that you post. Some companies may check your social media accounts before hiring, so think carefully about how you are presenting yourself online.

Misuse of social media such as to cause harm to the recruiting organisation, individuals or associates, or that may cause harm to RARE Youth Revolution will not be tolerated and will result in immediate dismissal from the internship programme.



Workplace etiquette and conduct

Meeting commitments and obligations

While undertaking your role, you will likely be required to participate in both internal and external company meetings. It is your responsibility to ensure that you arrive at these meetings on time and appropriately dressed, and that you conduct yourself in a professional manner.

Furthermore, it is part of your job to actively participate in meetings where appropriate. This is your chance to bring your ideas and thoughts to the table and to show what a valued member of the team you can be, so don't sit back and hide — dive in and get involved.

From a practical point of view, please ensure that when joining meetings virtually, you have an appropriate and clutter-free virtual background (no unmade bed or rude posters in the background please!), and ensure that background noise is eliminated to be respectful of the other participants (no TV, music or barking dogs).

Dress code, presenting yourself and representing the company

How we present ourselves to the outside world says a lot about who we are. Presenting yourself as a respectable professional is critical when representing an organisation. In your position, you will be representing both your employer and RARE Youth Revolution, so it is important to dress appropriately.

Make sure you know what the corporate dress code is during working hours, and ensure that you are in compliance with this when you are at work. If for any reason you are unable to comply with certain rules, for instance, you need a certain type of footwear that is usually discouraged in order to manage your medical condition, then speak to your employer about your needs. You should not be expected to sacrifice your health or dignity as part of a dress code.



Training

It may be necessary for you to take part in workplace training to support you in your role. This may be internal training or third-party training. When companies provide training, they are making a financial commitment to your career development, so you should engage fully with this process. It is often possible to list additional training that you have done as part of a role on your CV, so it is not only helpful for your placement but for your future job opportunities too.

Please ensure that you arrive on time to all arranged training sessions and that you complete all pre- and post-training work as requested.

If you have any accessibility needs in order to successfully engage with training, for instance, screen-reader software, captions or hearing loops, please make sure your organisation and trainer know about this in good time.

In addition to training offered by your company, RARE Youth Revolution will offer training sessions on CV writing and career development strategies to help you progress toward a fulfilling career. Please keep an eye on the RARE Youth e-news bulletins or contact your RARE Youth Coordinator for details of these sessions.

Health and safety, and fire safety

While you are working with your internship organisation, you will need to familiarise yourself with and abide by the company's health and safety policy. You may need to undertake some face-to-face or online training to prove that you have understood the requirements of the health and safety code, and the regulations related to fire safety.

If you require any specific adjustments to be made to help you exit the building in the event of a fire, please make your line manager and any designated fire safety representative aware as soon as possible after you start your role.

It is also appropriate to raise any concerns you have about your own health and safety within the organisation that the current policy does not cover or that you feel are not being addressed by the company itself. Your first port of call should be your line manager or health and safety representative.

Staying safe and supported in your role

It is of paramount importance to us that we, and your recruiting organisation, can work with you to create an internship that will allow you to thrive and maximise the opportunity for your career development. Here are some things that we can do together to help this happen.

Discussing your needs and ensuring necessary measures are in place

Before your placement commences, you will be given the opportunity to share your individual needs with the RARE Youth Revolution team so that we can advise your placement company and ensure that these are adequately catered for when you take up your position.

It is important that you are clear and honest about any limitations you may have or reasonable adjustments you may need, whether these are to support your physical or mental health. By talking openly to us, you will help us make sure that we find the right role for you and that your needs are adequately and consistently met during your internship.

Together, we will ensure that you know who is responsible for making the reasonable adjustments that you need and who your point of contact is to discuss any emerging issues, in recognition that rare diseases can be dynamic, and your needs may change over time.

What if I am uncomfortable speaking with my employer about my needs?

If you are uncomfortable speaking to your employer about reasonable adjustments or because your needs are not being met, you can contact your RARE Youth Coordinator for guidance on how to have this conversation, or so that they can speak to the company and advocate on your behalf.

How and who to ask for guidance

If you feel you need practical or emotional support during your internship, you can contact your RARE Youth Coordinator to help you arrive at a solution.

You may also be able to benefit from internal support depending on the organisational structure, such as from internal counsellors or mentors. You can enquire about this with your line manager or human resources.

Managing expectations

We know that sometimes things happen that mean we cannot always do our job to the best of our ability. This is especially true when working as a professional with complex health needs. As such, it is important that you **communicate any changes in your working capacity to your employer as soon as possible** and **keep a dialogue open**.

You should also **follow your company's internal policy** for reporting sickness or requesting additional reasonable adjustments to enable you, as an employee, to look after your health whilst doing your job. Make sure you are familiar with your company policy.

As a general guide, here is some advice on what to do when you encounter difficulties:

- If you cannot attend work due to ill health, you are required to **notify your recruiting organisation or line manager** at the earliest opportunity. You should make contact by email or by phone, unless otherwise advised. It is preferable to do this on your own behalf, but if it is unavoidable, a parent, partner or other named next of kin may do it for you
- If you cannot attend due to a planned or urgent medical appointment, you should **notify your recruiting organisation or line manager** as far as possible in advance of the appointment so that they can plan to cover for your absence or help you to reschedule your commitments
- We recommend that you also **notify your RARE Youth Coordinator** of any absences so that they are also aware

Managing workload based on ability

If you feel that the workload you have been assigned is too much, based on your physical or mental limitations, you **should speak with your line manager** so that your workload can be adjusted to reflect your needs.

If you need further support, please **contact your RARE Youth Coordinator**, who will be able to guide you through this and help support you in advocating for your needs.

Working with a personal assistant

Many within the rare disease community benefit from the support of a personal assistant to provide valuable help in their day-to-day lives. The following provides some guidance on how personal assistants might be used to support you in your internship.

Proper use of a personal assistant

If you require a personal assistant, it will be important that they are not misused in pursuit of your internship position. The personal assistant will be there to facilitate you doing your job. They should not be performing any of your duties for you, and they are not to be misused by your employer as an extra employee, i.e. performing tasks unrelated to you or your direct work.

You should declare within your initial application and or interview if you anticipate your personal assistant to be present during your working hours.

Non-disclosure for the personal assistant

Like yourself, your personal assistant will need to know what information can and cannot be shared outside the company to be sure that no confidential information is leaked. As such, a personal assistant who will be with you during working hours will be required to sign a non-disclosure agreement.

If you feel that your personal assistant is being misused by your organisation, please speak with your line manager. If you do not feel that the matter has been resolved, please contact your RARE Youth Coordinator to liaise with your recruiting organisation on your behalf.

Keeping safe in the workplace

Safeguarding is a term used to refer to the responsibility of the recruiting organisation to keep you safe and protected during your time with them. It is often linked to the company's health and safety policies, but it is also a legal requirement. Also, you have personal responsibility for your own safety and that of others around you.

The obligations and responsibilities of your organisation may differ depending on the nature of your role, so please ensure that you are aware of and have a copy of your organisation's safeguarding policy, which you should familiarise yourself with when joining.

If you are under 18 years old, you may also find it helpful to review the UK's legal requirements that all organisations must adhere to when working with young people.

www.hse.gov.uk/youngpeople/law/index.htm

Those who are over 18 years old should review the guidance here:

www.hse.gov.uk/pubns/indg450.htm

If you feel unsafe at work at any time and you feel you are unable to discuss your fears with anyone at your recruiting organisation, you can contact the RARE Youth Revolution team immediately for support and guidance. A copy of the RARE Youth Revolution Safeguarding Policy can be found in Appendix A.



Taking care of your mental health

We know that new experiences and situations can feel overwhelming, so taking care of your mental well-being is paramount during this process.

If you feel you need to talk to someone — reach out.

You might also find the following links useful:

- NHS: www.nhs.uk/mental-health
- MIND: www.mind.org.uk/information-support
- Hub of Hope: <https://hubofhope.co.uk>
- NHS LGBTQIA+: www.nhs.uk/mental-health/advice-for-life-situations-and-events/mental-health-support-if-you-are-gay-lesbian-bisexual-lgbtq
- ReThink LGBTQIA+: www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/lgbtplus-mental-health
- ReThink BAME: www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/black-asian-and-minority-ethnic-mental-health
- Barnardos: https://helpline.barnardos.org.uk/?gclid=Cj0KCQjwm9yJBhDTARIsABKlcGb8xpSNJWZIVRZY567_-b417Q4egHE8jeRBpzX2MtFWrEiNeGc5gAwaAtleEALw_wcB

Diversity, equality, and inclusion

RARE Revolution and all aspects of our business are committed to being an organisation that embraces diversity, equity and inclusion through every aspect of its governance, staffing and distribution of resources.

As such we expect the same from those with whom we partner, and those who engage in this programme whether it be as an intern or a partner organisation.

You may wish to share certain information with your employers to help them make you feel included:

- Your preferred name
- Your preferred pronouns
- Your ethnicity (e.g. British Indian, African American, etc).
- Your religion
- Your disability needs

You are **not required to disclose any of the above**, nor are you required to disclose your gender, sexual orientation or marital status, or a pregnancy.

Under UK employment law, there are **eight protected characteristics** that must not be discriminated against within the workplace. These are:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation

You can read more about protected characteristics and UK legal requirements here: www.equalityhumanrights.com/en/equality-act/protected-characteristics

If someone refers to you incorrectly or makes an assumption about your identity, it is perfectly acceptable to politely correct them. If you feel that they are continually addressing you incorrectly or that you are being bullied or harassed for any aspect of your identity, you should contact your line manager, your human resources representative and your RARE Youth Coordinator.

Accessibility

Should you wish to receive this guide in an alternative format please contact us at hello@rareyouthrevlution.com and we would be delighted to assist, so that you can access our information and programme in a way that works for you and your needs.

Legal rights

Your legal rights will vary depending on the terms of your particular chosen internship, and it will be the responsibility of the placement organisation to ensure that you are provided these at the commencement of your internship.

Should you have any queries you can contact your RARE Youth Coordinator at any time.

You may also find the following links helpful:

- www.gov.uk/browse/disabilities/rights
- www.legislation.gov.uk/ukpga/2010/15/contents
- Sick leave and holiday entitlement

FAQs

Can I apply for more than one role at a time?

Yes, absolutely! If you see more than one placement that is of interest, please feel free to apply for more than one place. However, you would only be eligible to take part in one placement at a time, so we would advise that you state any preference at the time of application.

What next if I am unsuccessful in my application?

If you are unsuccessful this time, please don't be deterred. Your dream placement is out there. Keep an eye out on the notice board for future positions to apply again in the future. We also recommend you talk to your RARE Youth Coordinator to discuss the sort of roles that appeal to you so that they can keep in touch about new opportunities.

Do I need any specific qualifications/experience?

This will vary depending on the particular opportunity. You will find all of the eligibility criteria, specific to each job within the job listing, so please check these before applying.

Can I change roles if I believe the one I have been assigned is not suitable?

If you feel the role is not right for you, please speak to your line manager and RARE Youth Coordinator at the earliest opportunity so that alternatives can be discussed. We cannot guarantee that an alternative role will be available within the same organisation, but you would be eligible to apply for future positions in other organisations if this is not the case.

Will I be paid for my internship?

This will vary depending on the particular opportunity. You will find all the terms for each job within the job listing, and this will include if this is a paid or unpaid opportunity.

How long will it take for my application to be processed and accepted or denied?

This will vary depending on the role and closing date, but your RARE Youth Coordinator will keep you updated at every step of the way.

Will there be internships available in my area?

The best thing to do is search the posting notice board to see what is available in your area; and remember to be open-minded about home working opportunities as these may open up the available opportunities considerably.

Do I need to disclose my health condition to my recruiting organisation?

You only need to share what you are comfortable sharing, but please be reassured that this programme is dedicated to supporting young people living with rare disease so everyone involved is invested in supporting your personal growth while acknowledging your health challenges.

Can my personal assistant accompany to my position if it is office based?

Yes, they can. Please refer to page 10 for details on this.

Can I remain in contact with the company after the internship has ended for future job opportunities?

We highly recommend that you do, and that you nurture the professional relationships made. Please refer to page 8 for details about what will happen with your internship comes to an end.

We hope that this comprehensive guide has given you sufficient information to go ahead and apply for your dream internship with confidence. However, should you have any outstanding questions please do not hesitate to contact your RARE Youth Coordinator at hello@rareyouthrevolution.com

Then head over to www.rareyouthrevolution.com/internship to hit APPLY

Wishing you all the best in your future internship!



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