

DRAFT DOCUMENT

Chronic Granulomatous Disorder Research Trust

Award

TERMS AND CONDITIONS OF GRANT

Third Edition

Registered Charity number 1003425

CGD Research Trust, Manor Farm, Wimborne St Giles, Dorset BH21 5NL

Terms and Conditions of Grant

Contents	Page
1. Definitions and Interpretation	1
2. These Terms and Conditions	3
3. General	4
4. Funding Arrangements	5
5. Accounting and Payments	6
6. Audit	7
7. Management of the Grant	8
8. Staff	8
9. Equipment	10
10. Monitoring and Reporting	11
11. Final Report	11
12. Final Invoices	12
13. Site visits	12
14. Publication	12
15. Communication	13
16. Media	14
17. Ethics	14
18. Use of Animals	14
19. NHS Framework	15
20. Confidentiality of Personal Data	15
21. Anonymising Data	15
22. Rights to Data	16
23. Depositing Data	16
24. Intellectual Property Rights (IPR)	16
25. Scientific Integrity	18
26. Suspension, Termination and Repayment of the Grant	19
27. Termination of the Grant by the Institution	20
28. Limitation of Liability	20
29. Dispute Resolution	20
30. The Contracts (Rights of Third Parties) Act 1999	21

Draft TERMS AND CONDITIONS 2006

31.	Variations to these Terms and Conditions	21
32.	Acceptance of the Grant	21
33.	Force Majeure	21
34.	Survival	21
35.	Jurisdiction and Governing Law	21

CGD Research Trust

Terms and Conditions of Grant

Grant Award Ref: J4G/

RESEARCH INSTITUTION: *[Name and address]* (the “**Institution**”)

PROJECT: *[Insert brief details]* and more particularly set out in the Application Form, as defined below, (the “**Project**”)

GRANT OF *[[£]Total]* (the “**Grant**”) **OVER** *[Number of months]*

DETAILS OF ANNUAL PAYMENTS:

Financial Year	Salary	Consumables	Travel & Subsistence	Exceptional Items	Equipment	Total
	[£]	[£]	[£]	[£]	[£]	[£]

1

2

3

1. Definitions and Interpretation

1.1 In these Terms and Conditions the following words, unless the context requires otherwise, have the meanings set out below:-

“**Agreement**” means these Terms and Conditions, the Application Form and the In Principle Award Letter;

“**Application Form**” means the Application Form completed by the Institution relating to the Project as approved by the Charity;

“**Background IPR**” means Intellectual Property Rights, the subject matter of which is connected to the Project and owned or controlled by the Institution as of the date of this Agreement;

“Budget”	means the budget set out in the Application Form amended, as appropriate, in the In Principle Award Letter;
“Charity”	means the Chronic Granulomatous Disorder Research Trust, registered charity number 1002425;
“Commencement Date”	means the date the Charity notifies the Institution in writing of the award of the Grant in accordance with the terms of the In Principle Award Letter;
“Equipment”	means any equipment purchased by the Charity in accordance with the terms of this Agreement;
“Foreground IPR”	means Intellectual Property Rights resulting from or created in connection with the performance or implementation of the Project by the Institution (“ Project IPR ”) together with any and all other Intellectual Property Rights that are derived from Project IPR at any time;
“Grant Period”	means the period over which the Grant is payable to the Institution in accordance with this Agreement;
“Intellectual Property Rights”	means all intellectual and industrial property rights including patents, know-how, registered trade marks, registered designs, utility models, applications for and rights to apply for business names (including internet domain names and email addresses), unregistered design rights, unregistered trade marks, rights to prevent passing off for unfair competition and copyright, database rights, topography rights and any other rights (whether registered or unregistered) in any invention, discovery or process, in each case in the United Kingdom and all other countries in the world and together with all applications therefor and all renewals and extensions;
“In Principle Award Letter”	means the letter from the Charity to the Institution confirming the award of the Grant in principle;
“NHS Framework”	the Department of Health’s Research Governance Framework for Health and Social Care;

“Patent Applications”	means any patent applications filed in respect of all or part of the Foreground IPR;
“Principal Researcher”	means the applicant detailed as “Applicant 1” on the Application Form;
“Researcher”	means the applicant(s) detailed on the Application Form, which unless stated to the contrary in these Terms and Conditions shall include the Principal Researcher;
“Staff”	means the persons engaged by the Institution for the purposes of the Project, including the Researcher, (whether employed or self-employed, part-time or full-time, as employee, consultant, student or in any other capacity); and
“Terms and Conditions”	means these Terms and Conditions of Grant, as varied or supplemented by the special conditions of grant (if any) set out in the In Principle Award Letter.

1.2 In these Terms and Conditions, unless the context requires otherwise:-

1.2.1 words importing the singular shall include the plural and visa versa;

1.2.2 references to any gender shall include all other genders; and

1.2.3 references to any statute or statutory provision include a reference to that statute or statutory provision as amended, consolidated or replaced from time to time (whether before or after the date of these Terms and Conditions) and include any order, regulation, instrument or other subordinate legislation made under the relevant statute or statutory provision.

2. These Terms and Conditions

2.1 These Terms and Conditions, signed by an authorised representative of the Institution in accordance with Clause 32 below, together with the Application Form and the In Principle Award Letter constitute a legally binding agreement between the Charity and the Institution.

2.2 In the event of an inconsistency between the Terms and Conditions and the terms of the Application Form and the In Principle Award Letter, in the absence of an express written statement by the Charity to the contrary, these Terms and Conditions shall prevail.

2.3 These Terms and Conditions will remain in force as follows:-

- 2.3.1 for the period of one year following payment of the last instalment of the Grant;
- 2.3.2 so long as any part of the Grant remains unspent;
- 2.3.3 so long as any Terms and Conditions remain unperformed or any breach of the same continues;

whichever shall be the longer.

3. General

- 3.1 The Grant must be used by the Institution only for the purposes of the Project.
- 3.2 The Institution shall ensure that the Project is completed within the agreed period according to the Budget. If the Institution needs to make material changes to the Project (for reasons including a failure to gain access to certain research facilities and services) to enable it to complete the Project within the agreed period in accordance with the Budget, it agrees to notify the Charity in writing as soon as possible prior to making such material changes. The Institution agrees to submit proposals for such material changes and the Charity may:
 - 3.2.1 agree to such material changes in writing;
 - 3.2.2 request that the Institution submit revised proposals to the Project prior to granting such an approval;
 - 3.2.3 make revisions to the existing Grant;
 - 3.2.4 draw up a new grant in place of the existing Grant; or
 - 3.2.5 withdraw the existing Grant and terminate the Agreement.
- 3.3 This Agreement will commence on the Commencement Date. The Project will commence no later than twelve months from the Commencement Date. The award of the Grant will automatically lapse if the Project does not commence twelve months after the Commencement Date, unless the Charity, on notification by the Institution, agrees to a time extension and confirms this in writing.
- 3.4 The Institution shall advise the Charity of the starting date of the Project at the earliest opportunity.
- 3.5 The Institution warrants that in undertaking and performing the Project it shall use all reasonable care and skill as to be expected from an Institution of its standing and shall work in accordance with good practice and appropriate professional guidelines. The Institution undertakes only to employ Staff with suitable and relevant qualifications and experience for a Project of this nature.

4. Funding Arrangements

- 4.1 Subject to the terms and conditions of this Agreement, the Charity shall pay the relevant Annual Payment as specified above in each Grant Year but shall have no other payment obligations to the Institution, the Staff or any third party in connection with the Grant. The Charity shall not be required at any time to pay any amount other than or in excess of each Annual Payment and the Institution shall be responsible for payment (out of the Annual Payment or such other funds as are available to the Institution) of any and all costs, expenses and all taxes payable in connection with the Grant and the employment of the staff employed on this award. The Institution shall protect, indemnify and hold the Charity and its officers, directors, employees and agents (“**Personnel**”) harmless from and against any costs, expenses and taxes incurred by the Charity in connection with the Grant.
- 4.1.1. The Budget sets out a **maximum** level of support to cover the actual expenditure incurred in carrying out the Project. Monies remaining in the Budget at completion of the Project cannot be made available for other purposes and must be declared to the Charity. Such underspends shall be recoverable by the Charity from the Institution and paid within [14] days of request by the Charity.
- 4.2 Project expenditure incurred outside of the Grant Period or above the Budget cannot be considered, unless prior written approval has been sought and obtained in writing from the Charity.
- 4.3 The Researcher may not be in receipt of any emolument or financial assistance from another source in respect of work the same or similar to the Project except with the knowledge and express written approval of the Charity.
- 4.4 The Project may be put into abeyance for a limited period with the prior written approval of the Charity.
- 4.5 The Researcher may work independently or under the direction of or in partnership with other research workers, who may or may not also be receiving support from the Charity.
- 4.6 Grants for salaries and recurrent expenses will normally be fixed at an annual rate. It is important that the Application Form states the salary scales which are current at the time the Application Form is submitted to the Charity and **includes** any proposed or estimated future pay awards. The Grant is fixed and no increases will be allowed except in exceptional circumstances and at the sole discretion of the Charity.
- 4.7 The Charity is entirely dependent upon funds from voluntary sources and the Grant will therefore be payable subject to the continued availability of funds (and satisfactory progress reports and compliance with these Terms and Conditions).

5. Accounting and Payments

- 5.1 Expenditure must be incurred in the Financial Year specified for that Annual Payment in the Application Form and/or the Details of Annual Payments contained in these Terms and Conditions, quoting the grant reference number and name of the Institution and the Researcher.
- 5.2 Claims for the reimbursement of expenditure should be made on a quarterly basis in arrears and should include all costs incurred in that period. In exceptional circumstances claims will be considered after this period, but will be paid at the sole discretion of the Charity. No claim for reimbursement will be considered more than six months after the expense was incurred.
- 5.3 The Charity may withhold payment of the Grant at any time in accordance with Clause 26 should it become apparent that reasonable progress on the Project is not being maintained.
- 5.4 Payments will be made by cheque cleared through a UK bank.
- 5.5 If the Project is being undertaken overseas, the total value of the Grant (including travel, consumables and all other expenditure) will remain fixed in the currency and in the amount set out in this Agreement and shall not be affected by fluctuations in the applicable exchange rate between sterling and, if different, the currency in which the Grant is to be paid.
- 5.6 All claims must be made by reference to the Budget and the relevant expenditure must be set out under the relevant Budget headings such as salaries, consumables, animal costs, travel and equipment (if applicable).
- 5.7 Copy invoices must be provided with all claims for non-salary items costing £500 (or the equivalent if the Grant is made in a foreign currency) or more.
- 5.8 Claims for salaries must give separate details of charges for basic salary, all forms of employee taxation or other governmental contributions and details of any location of role based allowances. The name of the individual to which the salary relates must also be stated.
- 5.9 The Charity will not reimburse VAT (or any other national equivalent or similar form of taxation) on the purchase of Equipment. Equipment is covered under the concessions in the Value Added Tax Act 1983 Schedule 5 Group 16. All Equipment must therefore be ordered by the Institution in accordance with the requirements of the Act.
- 5.10 The Charity will not consider payment of indirect costs (unless specifically requested in the Application Form and approved by the Charity), examples of which include: institutional overheads; subscription charges to professional organisations; registration and travel to conferences; financial services; personnel services; recruitment costs; public relations; institutional libraries; departmental services (administration, secretarial, printing, photography); telephone charges; postage and courier services.

- 5.11 Funds requested for specified purposes in the Application Form must be used for those purposes only. Virement between expenditure headings in the Application Form is only permissible with the prior written approval of the Charity.
- 5.12 The Institution is required to have in place formal purchasing procedures that ensure only valid Grant expenditure is claimed. The Grant may be terminated or payment withheld in accordance with Clause 26 below if such procedures are found not to be in place.
- 5.13 If at any time an overpayment of the Grant has been made for any reason whatsoever, the amount of such overpayment will be taken into account in assessing further payments, or will be recovered from the Institution at the Charity's discretion to be paid promptly on request.
- 5.14 The final claim for payment of Grant monies will only be accepted by the Charity if it is submitted by the Institution within three months of the end of the Grant Period.

6. Audit

- 6.1 The Charity reserves the right to ask for confirmation from the external auditors of the Institution of the following:-
 - 6.1.1 that the annual accounts of the Institution have been approved by the auditors without qualification;
 - 6.1.2 that the management letter from the auditors confirms that proper systems of control were in place and that there were no matters that did or could significantly effect the administration of the Grant; and
 - 6.1.3 that the Grant has been used for the purposes for which it was awarded.
- 6.2 The Charity may, at its discretion and cost, decide to commission a separate audit of the Grant and/or the systems used by the Institution to administer the Grant, including the system of equipment procurement, and, in so doing, it may or may not seek to use the internal audit function of the Institution.
- 6.3 The Charity may at its discretion undertake or have undertaken a separate audit of the Institution's accounting and payment to the Charity of all sums due to the Charity under these Terms and Conditions. In this regard, no more than once in any calendar quarter, upon reasonable advance notice to the Institution, the Charity or its appointed auditors may enter the Institution's premises during working hours in order to conduct such audit. The Institution shall provide the Charity with such reasonable assistance, including access to the Institution's technology, materials, assets, products, inventions, formulas, discoveries, information or data in which any Foreground IPR subsists or which were created in the course of or in connection with the Project, to enable the Charity to verify the Institution's compliance with these Terms and Conditions. The Institution shall maintain all appropriate records necessary to enable the Charity to conduct such audit. In the

event that the audit reveals that the Charity has not been paid any amount due to it in full under these Terms and Conditions by the applicable date for payment, without limiting any other remedies, the Institution shall immediately pay the Charity the unpaid amount, together with interest on such amount at 2% above the then applicable base rate of [Lloyds Bank plc]. The Institution shall also pay at the same time all the costs and fees incurred by the Charity in connection with such audit if the value of the unpaid amount is equal to or greater than 5% of the amount that the Institution should have paid to the Charity under these Terms and Conditions.

7. Management of the Grant

- 7.1 The Institution will ensure that the Association of Medical Research Charities' Guidelines on Good Research Practice are followed in connection with the Project.
- 7.2 The Institution accepts overall responsibility for the Grant.
- 7.3 The Principal Researcher must be actively engaged in the direction of the Project.
- 7.4 Any other Researchers must be actively involved in the running of the Project.

8. Staff

- 8.1 In all cases, the Institution shall be employers of staff in accordance with all applicable laws in the country in which the Institution is situated. The Charity will not be responsible for claims under any statute, federal or local laws or at common law in relation to, nor any liabilities arising from, the employment of Staff, nor will it indemnify the Institution against any claim for compensation or against any other claims for which the Institution may be liable as an employer.
- 8.2 The Charity must be informed of every member of Staff employed on the Grant whose details are not shown on the Application Form.
- 8.3 In any advertisement for Staff to be appointed in connection with the Project the Institution will state that the Project is funded by the Charity and will contain the logos and text set out in Schedule 1. The Institution will advise the Charity of details of each appointment as made.
- 8.4 Any new Staff recruited by the Institution as a result of the Grant must be recruited in accordance with the best practice procedures prevailing in the field in which the Institution operates.
- 8.5 With regard to all Staff, the Charity must be notified in writing of any changes in appointment; of any extended absences, such as maternity leave; or of any other circumstances that halts progress or causes delay to the Project.
- 8.6 All full-time members of Staff are expected to devote a minimum of 90% of their time to the Project.

- 8.7 Staff must not be appointed to a level of salary higher than that confirmed in the In Principle Award Letter without prior written agreement of the Charity or unless there is a national pay increase. Salary increases other than national pay awards must be met by the Institution.
- 8.8 Staff gradings and salaries must have the approval of the administrative officer of the Institution.
- 8.9 The Institution guarantees payment of the salary of the Principal Researcher during the term of the Grant.
- 8.10 Salary and other expenses must be administered through the relevant financial departments of the Institution and paid in accordance with all laws relevant to the location of the Staff.
- 8.11 The Institution shall in connection with all aspects of the Project, accept full responsibility for the management, monitoring and control and compliance with all applicable laws, regulations, codes of practice and guidelines governing the use of radioactive isotopes, animals (see also Clause 18 below), pathogenic organisms, genetically manipulated organisms (GMOs), toxic and hazardous substances, and research on human subjects and human embryos (see also Clause 17 below).
- 8.12 The Institution shall ensure that all Staff receive training appropriate to their duties, in accordance with the UK regulations set down under The Control of Substances Hazardous to Health Regulations 1999 (COSHH), the Advisory Committee on Dangerous Pathogens (ACDP), the Advisory Committee on Genetic Modification (ACGM), the Health and Safety at Work Regulations and any other regulatory requirements as may apply from time to time. For Staff involved in the Project and employed by an Institution from outside the UK, the Institution shall ensure that such Staff receive training appropriate to the applicable safety legislation, regulations or guidelines from time to time in force.
- 8.13 The Institution shall be responsible for maintaining appropriate policies of insurance covering professional public liability and employers' liability insurance and it shall provide evidence of such cover to the Charity upon request.
- 8.14 The Institution shall obtain and maintain:
- 8.14.1 appropriate cover for the Institution and the Staff with a professional medical defence insurance for any Project activities not covered by NHS indemnity arrangements or by any additional insurance provision made by the Institution; and
 - 8.14.2 registration for the Institution and the Staff with the applicable regulatory bodies in their location.
- 8.15 The Charity will not, save in exceptional circumstances, be willing to consider requests for additional Grant monies for salary purposes (including absence of Staff due to sickness or injury). Consequently any increments or other salary increases not identified in the Application Form will be the responsibility of the Institution.

- 8.16 The Charity will not pay the cost of maternity leave for Staff funded by the Grant. As the employer of Staff, the Institution will be obliged to pay any statutory or contractual maternity payments from funds not comprising Grant monies. If a member of Staff is due to take maternity leave, the Institution should inform the Charity of the dates in advance so that the relevant part of the Grant can be suspended for the period of maternity leave until full-time employment is resumed. Should alternative arrangements be proposed, including temporary appointments or return to work on a part-time basis, the Charity's permission must be obtained in writing prior to the commencement of the relevant maternity leave. The Charity must be consulted in connection with all decisions regarding temporary or permanent replacement of Staff and extended absences for sick leave.
- 8.17 The tenure of appointment of Staff must be confined strictly to the Grant period unless the Charity wishes to retain the Staff beyond this period for its own purpose and at its own expense.
- 8.18 If the Researcher wishes to move to another institution any unpaid or unspent Grant monies will not be transferred with him unless the Charity gives the Institution prior written approval.

9. Equipment

- 9.1 Equipment is to be used in the department in which the Researcher currently works, and primarily and mainly for the Project. The Equipment may only be used for other research provided this in no way interferes with or delays the Project research. The Charity reserves the right to require a full or partial repayment of the Grant in accordance with Clause 26 below, should the Equipment cease to be used for research into chronic granulomatous disease or other primary immune deficiencies or related illnesses.
- 9.2 The Charity reserves the right to see the original quotations and the original invoice issued for Equipment and (in accordance with Clause 26 below) to withhold or recover any payments if the Institution does not provide this documentation on request.
- 9.3 Responsibility for Equipment lies with the Institution, in particular the Institution will be responsible for its accommodation, operating and servicing costs and any insurance that may be necessary.
- 9.4 If any Equipment is damaged or destroyed during its useful lifetime the Institution will be required to repair or replace it.
- 9.5 Unless the Charity agrees to the contrary, Equipment should carry a prominent label or plaque showing that the Charity funded it.
- 9.6 Without prejudice to Clause 9.7 below, should the Researcher move to another research institution during the Grant Period or within one year of the expiry of the Grant Period, the Charity reserves the right to require that the Equipment be transferred with him/her, at no cost to the Charity, after discussion, if necessary, with the research institution concerned.

- 9.7 Equipment must not be disposed of or removed from the Institution without the Charity's prior written approval. Where Equipment has been purchased solely by the Grant, the net proceeds from disposal, or upon removal the relevant amount of the Grant used to purchase the Equipment, must be returned to the Charity. Where Equipment has been purchased jointly between the Institution and the Charity, the Charity reserves the right to receive a proportionate amount of the net proceeds upon disposal or a proportion of the relevant amount of the Grant used to purchase the Equipment upon removal.
- 9.8 In exceptional circumstances, special Terms and Conditions in relation to highly specialised items of Equipment may be detailed in the In Principle Award Letter.
- 9.9 Should any ancillary activity be carried out using the Equipment for commercial gain then the Charity's prior written approval must be obtained and such agreement may be conditional and dependent upon the Charity sharing in any financial benefit that results.

10. Monitoring and Reporting

- 10.1 Regular informal contact with the Charity to discuss Project progress is welcomed.
- 10.2 Whatever the Grant Period, yearly continuation will depend upon receipt of high quality annual reports. Annual reports should be written in accordance with the Charity's 'Guidelines for preparation and submission of reports on research supported by a CGD Research Trust grant' and must be received within three weeks of each anniversary of the start date of the Project.
- 10.3 During the Grant Period the Institution shall provide a detailed written progress report every six (6) months from the Commencement Date along with such other verbal or written progress reports as the Charity may request from time to time.
- 10.4 In the extreme case of contemporary research developments negating the meaningful continuation of the Project the Charity reserves the right to request re-orientation of the Project or to discontinue the Grant.

11. Final Report

- 11.1 It is a condition of the Grant that a detailed written report of the work carried out and a full expenditure report are submitted to the Charity within three months from the end of the Grant Period. If the final report and the final expenditure statement have not been received by the Charity in a form satisfactory to it within such period, the Charity may demand at its discretion up to 20% of the amount of the Grant from the Institution and the Institution hereby agrees to promptly repay such amount as the Charity may demand in such circumstances. The Institution must repay and hereby agrees promptly to repay the Grant and all payments made by the Charity in connection with it if the report and statement have not been received by the Charity in a form satisfactory to it within six months of the end of the Grant Period. Failure to provide the report and/or final expenditure statement in a form satisfactory to the Charity on a timely basis may preclude any subsequent grants to

- the Institution, and to any collaborators/co-grant holders. The final report must be written in accordance with the Charity's 'Guidelines for preparation and submission of reports on research supported by a CGD Research Trust grant' which are attached hereto.
- 11.2 The Charity reserves the right to send the final report for external review. Comments made by reviewers will be submitted to the Institution, and where justified, will be used by the Institution to produce a revised final report.
- 11.3 The Charity will withhold the last quarterly payment of the Grant until the final report has been received and approved by the Charity.
- 11.4 The Charity reserves the right to reproduce the findings of the final report or to provide a summary of their findings.
- 11.5 Where volunteers are involved in the Project research, the Institution is required, within the bounds of relevant ethical framework, to provide feedback to the volunteers or their carers at appropriate stages during the Project.

12. Final Invoices

- 12.1 Final invoices must be received within three months from the end of the Grant Period. No payment will be made in respect of invoices received after this date.
- 12.2 Final invoices will not be paid until the final report and lay summary produces in accordance with Clause 13.1 above have been received and approved by the Charity.
- 12.3 The Charity shall close the Grant (and shall have no further obligation to make any Grant payment to the Institution) six months after the scheduled end of the Grant Period.

13. Site visits

- 13.1 The Charity reserves the right to inspect the Project at the Institution at any time during normal business hours by prior arrangement and upon giving the Institution reasonable notice of such requests, permission for which will not be unreasonably withheld.

14. Publication

- 14.1 The Institution will ensure that publication of findings in peer reviewed journals is sought as soon as possible during, and after conclusion, of the Project even where results prove negative. At least one reprint of each published paper should be submitted to the Charity.
- 14.2 The Institution will ensure that no restrictive publication arrangements regarding Project research papers are entered into without the prior consent of the Charity.

- 14.3 The Institution shall ensure that anyone listed on a Project research paper should accept full responsibility for ensuring that he/she is familiar with the contents of the paper and can identify his/her contribution to it. The Charity finds that the practice of honorary authorship is unacceptable.
- 14.4 It is the Charity's policy to publicise as widely as possible its grants and the scientific progress achieved through them. It is therefore a condition of accepting the Grant that the Institution agrees to ensure that the Principal Investigator co-operates in such publicity efforts.
- 14.5 The financial support of the Charity must be acknowledged in all publications, presentations, posters, print media and other forms of publicity arising from work on the Project. The acknowledgement must be stated either in the text or in a footnote, using the Charity's logo and text set out in Schedule 1. A reprint of such materials must be sent to the Charity.
- 14.6 The contribution of formal collaborators and all other others who directly assist or indirectly support the Project should be properly acknowledged.
- 14.7 The Charity reserves the right to require that the Institution makes clear in any published material that the conclusions of the Project research are not the views of the Charity. The Charity should be notified in advance when the Project research results might be published, publicised or disseminated. Where research findings are of special importance to patients the Institution shall ensure that it or the Researcher notifies the Charity, in confidence and/or under embargo if appropriate, of expected journal publication to enable preparation to be made to anticipate and manage enquiries from patients and the public and to enable the Charity to gain appropriate media coverage of the findings. The Institution shall ensure that all such materials are sent for approval to the Charity prior to publication and that one copy of all such materials will be submitted to the Charity at the time of publication. Such materials will be sent to the Charity for approval at least 7 days prior to publication.
- 14.8 The Institution shall help in any publicity regarding the Project in any Jeans for Genes Campaign USA – as requested by the Charity.
- 14.9 The Institution shall ensure that whenever it makes any references to primary immunodeficiency diseases in any print, broadcast or electronic media, the Institution will always include a mention of the Charity and its work.

15. Communication

- 15.1 It is a condition of the Grant that the Researcher will speak / make a presentation at any event organized by the Charity (reasonable expenses for which will be met by the Charity) and will co-operate in the preparation of articles for publication on behalf of the Charity, attending Charity family days and medical conferences as reasonably required by the Charity.

16. Media

- 16.1 The Institute shall ensure that the Charity is contacted before either contacting the media or making comment to the media on the Project or the Project research results.

17. Ethics

- 17.1 If the Project includes research on human subjects, sample or data it will be the responsibility of the Institution to obtain the following approvals as appropriate:-

17.1.1 approval from the Research Ethics Committee of the Institution;

17.1.2 Multi-Centre Research Ethics Committee approval;

17.1.3 Local Research Ethics Committee approval;

17.1.4 such approvals as would ordinarily be required in the country in which the Project takes place.

- 17.2 The Charity recommends that the Institution and/or the Researcher also contact any relevant professional or scientific body and in some cases, where appropriate, to seek the views of the relevant patient groups.

- 17.3 No part of the Grant shall be paid to the Institution and, save in exceptional circumstances, no part of the Project shall commence, until the Institution has provided the Charity with satisfactory evidence that all necessary approvals have been obtained.

18. Use of Animals

- 18.1 The Institution shall ensure, wherever possible, that procedures and techniques are adopted that avoid the use of animals, substituting them with other experimental techniques. Where this is not possible, the Institution shall design and carry out the research so that, in accordance with the guidelines issued by the Association of Medical Research Charities on “Promoting good practice in research involving animals” and the Biotechnology and Biological Sciences Research Council in the United Kingdom and any other guidelines on the use of animals that apply to the Institution:

18.1.1 the least sentient species with appropriate physiology is used;

18.1.2 the number of animals used is kept to a minimum; and

18.1.3 the severity of procedures and experiments performed on animals is kept to a minimum and appropriate anaesthesia, analgesia and humane end point techniques should be used to minimise any pain and suffering experienced by the animals.

- 18.2 The Institution will ensure that those involved with the Project read and observe the Association of Medical Research Charities’ Guidelines on *‘Promoting good*

practice in research involving animals' and, if the Institution is located outside the United Kingdom, all other equivalent guidelines that have been published by similar bodies of equivalent standing in the jurisdiction in which the Institution is located.

18.3 Where the Project is subject to regulation by the Animals (Scientific Procedures) Act 1986, the provisions of the Act and additional regulations must be observed with respect to both the spirit and the letter of the law. Where the Project is conducted outside of the UK the Institution shall ensure the compliance with all applicable scientific procedure on animal laws. Applications for all licences and certificates required under the above Act or any equivalent national law must be made to the Home Office or relevant government or agency direct through the Institution's normal channels. It is recommended that these channels include review by an animal care and use committee.

18.4 The Institute shall ensure that the Project does not commence until all necessary licences have been obtained.

19. NHS Framework

19.1 The Institute shall ensure that the Project is conducted in accordance with the NHS Framework if and when this comes into force.

19.2 The Institute confirms that it will undertake the role of "Research Sponsor" and the Principal Researcher will undertake the role of the "Chief Investigator" as defined respectively in the NHS Framework.

20. Confidentiality of Personal Data

20.1 The collection, handling and use of data relating to individuals shall be treated as confidential at all times.

20.2 Data must be held in accordance with the Data Protection Act 1998 or the equivalent national laws relating to the protection of personal data in force in the location of the Institution and any additional protocols adopted by the Charity.

20.3 No information that would lead to the identification of an individual shall be included in any publications without the prior agreement in writing of the individual concerned. No mention shall be made of individual officers of the Institution, nor shall information be included that might lead to their identification, without the prior agreement in writing of the Charity.

21. Anonymising Data

21.1 To safeguard the confidentiality of personal data the Institution shall ensure that all basic factual data is anonymised and that the key to the identities of persons involved in the Project is kept in a separate and secure place.

22. Rights to Data

- 22.1 Subject to the provisions of Clause 20 above, the Charity reserves the right to have access to and use data compiled during the course of the Project and will respect existing guidance on confidentiality of any personal data that it contains.
- 22.2 The Institution shall ensure that relevant data and materials is made available to other researchers, on request, provided that this is consistent with any ethics approvals and consents, which cover the data and materials, the Data Protection Act 1998 (or any equivalent national laws on data protection applicable to the data) and any intellectual property rights in them.

23. Depositing Data

- 23.1 The Institute and/or the Researcher shall consider with the Charity the need for depositing both qualitative and quantitative data in a relevant data archive.

24. Intellectual Property Rights (IPR)

- 24.1 The Charity is committed to promoting research into the cause, inheritance, management of symptoms and cure of Chronic Granulomatous Disease. The Charity wishes (and is obliged as a matter of charity law) to ensure that the useful results of the Project research are published “for the public good”. At the same time, the Charity recognises the pressures upon research institutions and therefore the following clauses of this section are intended to pay due regard to both of these potentially disparate requirements.

For the purposes of this clause, references to:

“**exploitation**” of Foreground IPR means: (1) the sale, commercialisation or licensing of, or the undertaking of any commercial activity involving, any technology, materials, assets, products, inventions, formulas, discoveries, information or data in which any Foreground IPR subsists or which were created in the course of or in connection with the Project; (2) the sale, assignment, transfer or other disposal (whether in whole or in part) (“**transfer**”) of any Foreground IPR or the transfer or grant of any interest in such IPR; and (3) any other form of exploitation or use of any Foreground IPR for or in connection with any commercial activity.

“**commercial activity**” means any purpose or activity from which any revenue, benefit or other value is derived.

- 24.2 Title to all Background IPR shall remain with the Institution. Subject to the Institution’s compliance with these Terms and Conditions, title to Foreground IPR shall belong to the Institution.
- 24.3 The Institution shall:-

- 24.3.1 develop and implement strategies and procedures for the identification, protection and exploitation of the Foreground IPR or any inventions, discoveries, data or information created pursuant to the Project;
 - 24.3.2 unless otherwise agreed bear all costs incurred in connection with the preparation, filing, prosecution and maintenance of any Patent Applications files and all other applications for registration of any Foreground IPR by the Institution (“**Applications**”);
 - 24.3.3 keep the Charity advised as to the progress of any Applications, and provide the Charity with copies of all papers received and filed in connection with the Applications;
 - 24.3.4 not amend or abandon any Application or registration made in its sole name without first consulting with the Charity;
 - 24.3.5 notify the Charity promptly if any Foreground IPR or any inventions, discoveries, data or information that may be of medical or commercial value is created pursuant to the Project, and ensure that such Foreground IPR or such inventions, discoveries, data or information is protected and not published or otherwise publicly disclosed prior to protection (whilst at the same ensuring that potential delays in publication are minimised);
 - 24.3.6 ensure that all Staff are employed or retained on terms that vest the Foreground IPR in the Institution;
 - 24.3.7 ensure that the Foreground IPR is not exploited in any way without the prior written consent of the Charity. As a condition of the Charity granting such consent, the Institution will submit the terms and conditions of exploitation of the Foreground IPR for prior approval by the Charity.
 - 24.3.8 pay to the Charity on a monthly basis forty per cent (40%) of all revenues received in the prior month by the Institution, its subsidiaries or affiliates from the exploitation of Foreground IPR. Such payment shall be made into such UK bank account as the Charity specifies to the Institution from time to time.
- 24.4 The Institution shall at the request of the Charity provide the Charity with:-
- 24.4.1 an annual report setting out details of the exploitation of Foreground IPR for the period covered by the report, including any sums received in respect of such exploitation;
 - 24.4.2 copies of all agreements with commercial or other partners regarding exploitation of the Foreground IPR; and
 - 24.4.3 the right to audit the Institution’s relevant accounts.
- 24.5 Neither the Institution nor any member of Staff shall enter into confidentiality agreements with any other party where that party would place restrictions on the

- publication of or obtain knowledge of the results of the Project research or the Foreground IPR without obtaining the prior written approval of the Charity.
- 24.6 If the Institution decides not to file any Patent Application or otherwise proceed with the protection of any Foreground IPR, the Institution will promptly notify the Charity and fully co-operate (and ensure that the Staff co-operate) with the Charity so that the Charity will have an unreserved and unrestricted right, but not a duty, to file any Patent Application itself at its own cost and in its own name, or otherwise seek protection of the Foreground IPR and the Institution will not be entitled to share in any resulting profit or benefit. Such co-operation shall include the taking of all steps and execution of all documents as may be required to entitle the Charity to file and/or prosecute Patent Applications.
- 24.7 The Institution shall not without the prior written consent of the Charity assign, transfer or in any other way part with any rights in connection with the Foreground IPR.
- 24.8 In order to support the Charity's obligation to ensure that the useful results of the Project research are published for the public good, the Institution is required to and hereby does permit the Charity (free of charge) use of any copyright material created or acquired in connection with the Project except where, and only for so long as, such use involves publication of the material and any such proposed publication would be likely to:
- 24.8.1 prejudice the successful prosecution of any Patent Applications;
 - 24.8.2 infringe the intellectual property rights of a third party or amount to an unauthorised disclosure of information which is subject to obligations of confidence owed to a third party.
- 24.9 Occasionally it will be necessary for the Charity to require that all copyright and rights of a similar nature arising from the Project and capable of being conferred under the laws of the United Kingdom and such other relevant countries should be assigned to and vested absolutely in the Charity. At the request of the Charity, the Institution shall execute or procure the execution of such deeds and documents and do such other acts and things as may be necessary to achieve such assignment and transfer. When this is the case, there will be a specific condition in the In Principle Award Letter.

25. Scientific Integrity

- 25.1 It is a condition of Grant that the Institution is able to produce evidence of a procedure for dealing with scientific fraud. A viable mechanism for dealing with accusations of scientific fraud and other irregularities must contain the following elements: a guidance document or code of practice on standards of professional behaviour; provisions for induction and training of Staff; monitoring; regulations and procedures for handling allegations; fair procedures and appropriate protection for both the accused and the 'whistleblower'.

- 25.2 In the rare event of scientific fraud or other scientific irregularity occurring, it will be the responsibility of the Institution to investigate it.
- 25.3 If a case of scientific fraud is suspected in connection with the Project the Institution must notify the Charity immediately and keep the Charity promptly informed of further developments.
- 25.4 If the Institution fails to ensure that adequate steps are taken to proceed with the relevant investigation the Charity reserves the right to withhold payment of the Grant.
- 25.5 If fraud or any other irregularity is proven, the Charity will in accordance with Clause 26 below terminate the Grant immediately and Grant monies already paid will become repayable immediately.
- 25.6 The Institution agrees that at the request of the Charity it will promptly and actively investigate any allegation of scientific fraud.

26. Suspension, Termination and Repayment of the Grant

- 26.1 The Charity may withhold payment of all or part of the Grant, terminate the Grant and / or require repayment of some or all of the Grant at its sole discretion upon giving the Institution reasonable notice (except where these Terms and Conditions provide to the contrary) in the following circumstances:-
 - 26.1.1 in the circumstances specifically referred to in these Terms and Conditions; or
 - 26.1.2 if there is a breach of these Terms and Conditions which is either not remedied within 30 days of the Charity notifying the Institution that a breach has occurred which must be remedied or a breach is incapable of remedy; or
 - 26.1.3 reports or reviews of the Project are reasonably deemed to be unsatisfactory by the Charity or its external reviewers and after discussion with the Institution.
- 26.2 The Charity may terminate the Grant at its discretion at any time by providing at least 3 months notice to the Institution.
- 26.3 Upon termination of the Grant the Charity shall, subject to the provisions of Clause 5 above, reimburse the Institution for any expenditure properly and necessarily incurred under the Grant up to the termination date but it will not in any event be responsible for, nor indemnify the Institution against any other costs or liabilities. Claims for reimbursement of expenditure must be submitted to the Charity within three months of the Institution having received notice of termination.

27. Termination of the Grant by the Institution

- 27.1 In the event of the Project being discontinued by the Institution, written notification must be given immediately to the Charity setting out reasons for the termination of the Project, whereupon the Grant will automatically terminate unless the Charity confirms to the Institution in writing that this will not be the case.
- 27.2 Upon termination of the Grant under this clause:-
- 27.2.1 the Charity reserves the right to demand repayment of all or part of the Grant paid to the Institution up to the date of termination.
- 27.2.2 any claims made by the Institution for reimbursement of expenditure in connection with the Project must be submitted to the Charity within three months of the Charity having received notice of termination of the Project and payment of such monies will be made at the absolute discretion of the Charity.

28. Limitation of Liability

- 28.1 Notwithstanding any other provision of this Agreement other than Clause 28.3, to the maximum extent permissible under English law, the Charity will not be liable to the Institution for any losses including direct, consequential or indirect losses (including any loss of profit, data, goodwill or business opportunity) arising out of or in connection with this Agreement.
- 28.2 In the event that the Charity incurs any liability to the Institution that is not excluded pursuant to Clause 28.1, the maximum liability of the Charity to the Institution in aggregate, whether in contract, negligence or other tort or otherwise arising out of or in connection with this Agreement, will not under any circumstances exceed the 40% share of all revenues received by the Institution, its subsidiaries or affiliates from its exploitation of Foreground IPR and paid to the Charity pursuant to Clause 24.3.8.
- 28.3 The limitations and exclusions of liability set out in this clause shall not apply to physical injury or death to the extent that it is caused by the negligence of a party in connection with or arising out of this Agreement or in respect of fraud.

29. Dispute Resolution

- 29.1 Whether or not the Grant has been terminated, neither the Charity nor the Institution will take legal proceedings for the enforcement of the terms of this Agreement or of any rights arising under it, without first having taken positive steps to resolve the matter by negotiation, mediation or other informal method of dispute resolution not involving publicity.

30. The Contracts (Rights of Third Parties) Act 1999

- 30.1 The provisions of the Contracts (Rights of Third Parties) Act 1999 shall not apply to this Agreement.

31. Variations to these Terms and Conditions

- 31.1 Grants awarded by the Charity are subject to these Terms and Conditions. However, the Charity reserves the right to make reasonable changes to the Terms and Conditions from time to time and will promptly notify the Institution of any such changes and in such circumstances the revised Terms and Conditions will apply to the Grant.

32. Acceptance of the Grant

- 32.1 Before the Grant may be activated, the Institution must accept, and agree to abide by these Terms and Conditions by completing and signing page 16 of these Terms and Conditions and returning these Terms and Conditions to the Charity. These Terms and Conditions may only be signed by a senior staff member who has the authority to commit the Institution to the Agreement. Such an individual may be: The Principal, the Vice Chancellor or Dean, the Registrar, the Secretary, the Research Contracts Officer, the Bursar, the Finance Officer or the Chief Accountant of the Institution.

33. Force Majeure

- 33.1. Neither the Charity nor the Institution shall be held to be in breach of its obligations under the Agreement if its failure to meet its obligations caused by circumstances outside its reasonable control.

34. Survival

- 34.1 Clauses 5.13 (Accounting and Payments), 6 (Audit), 9 (Equipment), 14 (Publication), 16 (Media), 20 (Confidentiality of Personal Data), 21 (Anonymising Data), 22 (Rights of Data) and 24 (Intellectual Property Rights), 26 (Withholding Payment, Terminating or Requiring Repayment of the Grant by the Charity), 28 (Limitation of Liability), 29 (Dispute Resolution), 30 (The Contracts (Rights of Third Parties) Act 1999), 35 (Jurisdiction and Governing Law) and any other accrued rights and obligations of the parties which expressly or by implication come into or continue in force on or after termination of this Agreement will survive such termination.

35. Jurisdiction and Governing Law

- 35.1 This Agreement will be governed by and construed in accordance with English law and the parties hereby submit to the exclusive jurisdiction of the English courts.

CGD Research Trust

Terms and Conditions of Grant

Grant Award Ref: J4G/

RESEARCH INSTITUTION: [*Name and address*] (the “**Institution**”)

PROJECT: [*Insert brief details*] and as more particularly set out in the Application Form (the “**Project**”)

GRANT OF [[£]*Total*] (the “**Grant**”) **OVER** [*Number of months*]

DETAIL OF ANNUAL PAYMENTS:

Financial Year	Salary	Consumables	Travel & Subsistence	Exceptional Items	Equipment	Total
	[£]	[£]	[£]	[£]	[£]	[£]

1

2

3

SIGNED FOR AND ON BEHALF OF THE CGD RESEARCH TRUST

.....

Name (please print clearly):

Being an authorised representative of the CGD Research Trust

I HEREBY CONFIRM THAT I AM AN AUTHORISED OFFICER OF THE INSTITUTION, AND THAT ON BEHALF OF THE INSTITUTION, I ACCEPT THESE TERMS AND CONDITIONS OF GRANT

.....

DATE:

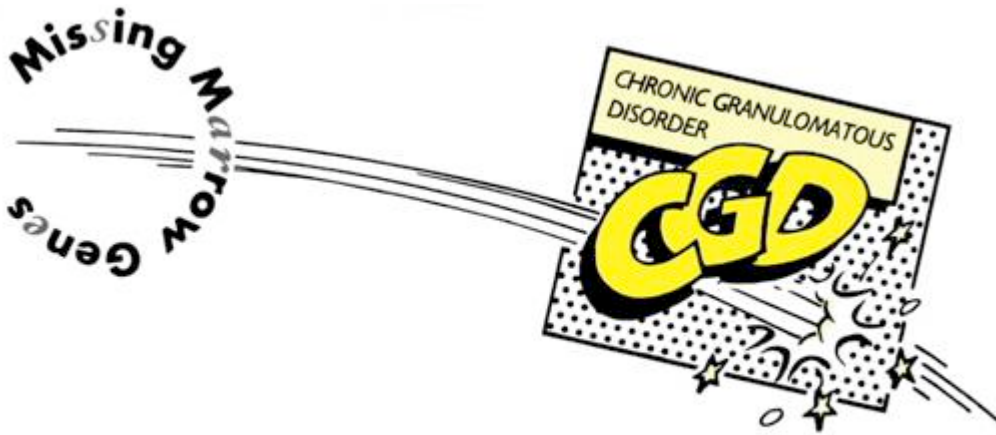
Name (please print clearly):

Title:

DATE:

Schedule 1

Logos



Text

This work is supported by a grant from the Chronic Granulomatous Disorder Research Trust (CGD/RT). CGD/RT is the founder partner of the Jeans for Genes Campaign and the owner of the registered trademark "Jeans for Genes".