Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392009

THE HAEMOPHILIA SOCIETY

. . . is the nationwide voluntary organisation founded to provide a fellowship for haemophiliacs and those concerned with their health and welfare.

... safeguards the social and economic interests of haemophiliacs and promotes the study of the causes and treatment of haemophilia and similar conditions.



THE HAEMOPHILIA SOCIETY



ANNUAL REPORT
Year Ended 31st December, 1964

Braeside Press, Norbury, S.W.16

THE HAEMOPHILIA SOCIETY

A Friendly and Charitable Organisation for the Welfare of Sufferers from Abnormal Bleeding.

(Registered in accordance with the National Assistance Act 1948 and the Charities Act 1960)

94 SOUTHWARK BRIDGE ROAD LONDON, S.E.1.

Telephone: WATERLOO 3007

President:

Sir WELDON DALRYMPLE-CHAMPNEYS, Bt., C.B., M.A., D.M., F.R.C.P., D.P.H.

Vice-Presidents:

R. G. MACFARLANE, C.B.E., M.A., M.D., F.R.C.P., F.R.S. H. F. RUTHERFORD, O.B.E., F.H.A. J. F. WILKINSON, Ph.D., M.Sc., M.D., F.R.C.P., F.R.I.C. LORD WILLIS OF CHISLEHURST.

Honorary Medical Advisory Panel: ROSEMARY BIGGS, M.D. KATHARINE DORMANDY, M.R.C.P. R. M. HARDISTY, M.D., M.R.C.P. A, F. H. BRITTEN, M.B., B.Ch. G. I. C. INGRAM, M.D., M.R.C.P. E. NEUMARK, M.D.

Honorary Dental Adviser: A. S. MOORE, L.D.S., R.C.S. Honorary Medical Social Worker: Miss J. A. JUDD, A.M.I.A.

Honorary Auditor: WALTER J. JANSEN, P.A.C.C.A., F.C.C.S., WESTMINSTER BANK LTD., WESTERN CHAMBERS, WESTERN ROAD, ROMFORD. ESSEX.

Bankers: BAKER STREET, LONDON, W.1.

With the growing interest in this subject the next two or three years may well be ones of crucial importance to all. It is, therefore, essential that all Members should continue to give their fullest support so that the Society may continue to make further useful contributions to the advances which we trust will surely come.

By way of concluding may I make a further reference to Dr. Dormandy. It is to thank her for the most commendable work she is doing for haemophiliacs, in particular amongst children, and by way of a tangible expression of our appreciation, I have pleasure in asking her to accept from the Society this cheque for £500. It is our fervent hope that it will enable you, Dr. Dormandy, to make still further progress in your researches. May I also express the hope that this cheque may be the first of many that will pass safely into your hands.

REPLY from Dr. Katharine Dormandy.

Mr. Rutherford, Members of the Committee and friends of the Haemophilia Society, I would like to thank you very much for all your kind words, for the caravan which we have and in which we are working, and for this financial aid to our work.

We did have some difficulty in the initial stages in obtaining financial assistance and in getting enough interest whipped up to get this project going; but now with your help and encouragement, with the help of the Medical Research Council, the London University, and the Ministry of Education, all the first hurdles are over and all that remains is for us to do the work.

Although we started off limiting this to London (that was only because I felt I couldn't intrude in other people's affairs) other places have already contacted us, first of all Oxford, and said, "please don't leave us out, can't you cover the whole of Great Britain?" We are, therefore, joining up with other Centres, we are preparing a report and we hope a preliminary report will go to the Medical Press within the next six months. We then hope to prepare recommendations as to what we think should and ought to be done.

So I thank you very much, all of you, and I expect you will all be helping us in your own way later on.

Many doctors are now regarding haemophilia as much a social problem as a medical problem. The Society, it is felt, can with justification, claim some of the credit for this broadening of the outlook. The Society has, as I have mentioned earlier, always been, primarily, a social and welfare organisation and will continue so to be; but since the Social and Medical problems are becoming more clearly related, a much closer link with the Medical Profession is desirable, in particular with those Doctors who are directly concerned with haemophilia.

It is, therefore, with particular pleasure I announce the formation of a Medical Advisory Panel and to this body the many problems of a Medical and Social-Medical nature can, and will be, referred. Approaches have been made and I am pleased to say that the following have agreed to serve on this Panel:—

Dr. Rosemary Biggs, who has for many years been closely associated with our Vice-President, Dr. R. G. Macfarlane, at the Medical Research Council's Blood Coagulation Research Unit at the Churchill Hospital, Oxford. Dr. Macfarlane and Dr. Biggs are among the world's foremost authorities on Haemophilia and allied disorders.

Dr. Katharine Dormandy of the Royal Free Hospital, London, whose activities and interests I have mentioned previously.

Dr. A. F. Britten, who has been a member of the Society for many years, and has worked in South Africa, Holland and the United States of America on blood disorders.

Dr. R. M. Hardisty, who is in charge of the Haemophilia Reference Centre at The Hospital for Sick Children, Great Ormond Street, London.

Dr. G. C. Ingram of St. Thomas' Hospital, London, who is in charge of the Reference Centre there.

Dr. E. Neumark of St. Mary's Hospital, London, who as you will know, has been Medical Adviser to the Society for a number of years.

The Society is most grateful to these distinguished scientists for their willingness to aid the Society in bringing relief to those suffering from haemophilia.

25th April 1965

The Annual General Meeting was held on Sunday, 25th April, 1965, at The Hospital for Sick Children, Great Ormond Street, London, W.C.1.

In the absence of the President, Sir Weldon Dalrymple-Champneys, who unfortunately could not be present, the Chair was taken by Mr. H. F. Rutherford, O.B.E., F.H.A., Vice-President of the Society.

Mr. Rutherford announced that at the Council Meeting held immediately prior to the Annual General Meeting, the President and Vice-Presidents had been unanimously reelected for a further year.

It was also announced that the Sir Lionel Whitby Memorial Award had this year been awarded to Mr. Howard Lee of Birmingham, who has shown considerable courage and endeavour in overcoming many difficulties in the pursuit of his studies and other activities.

The minutes of the last Annual General Meeting were agreed and signed following which the Annual Report, which had previously been circularised to all members, was presented to the Meeting by Mr. J. R. Hunter, the Honorary Chairman. (See Page 5.)

The adoption of the Annual Report was moved from the Chair and was agreed.

The election for the Office of Honorary Chairman then took place and Mr. J. R. Hunter was re-elected for a further year.

The other Honorary Officers and Executive Committee Members were returned unopposed as shown on the Notice of the Meeting.

The address was then given by Mr. Rutherford. (See Page 14.)

Honorary Officers and Committee elected 1965:

Honorary Chairman:

J. R. HUNTER, B.sc

Honorary Vice-Chairman:

Honorary Treasurer:

P. H. MORRIS

K. E. COOPER

Honorary Secretary:

K. R. POLTON

Committee Members:

Miss S. J. BRODIE F. J. ELLIOTT

A. PHILLIPS

Mrs. E. L. HUNTER J. B. CRAWLEY C. A. HUBBARD R. F. ROGERS

It has frequently been said that if only there were something specific to work for and to talk about to likely subscribers, funds could be raised. Surely then, "this is it", for here we have a golden opportunity of intensifying our efforts by not only the means we have used to raise funds in the past but by thinking out new ones too.

Funds will also be required to meet the cost of a survey which the Society proposes to carry out during the next few months and which will concern adult haemophiliacs. This, I understand, is primarily to ascertain the kinds of haemorrhage experienced, the frequency of the visits to hospital, the kind of treatment received and the extent to which these incidents affect the person's employment. This latter factor is, it will be appreciated, a great source of worry to many haemophiliacs. From these investigations it is hoped that improved facilities and treatments will be made available. To do this, of course, one of the primary furctions of the Society will be achieved.

The Society is grateful to the Ministry of Health for the sympathy shown to the numerous problems of the haemophiliac. This, I am happy to say, has continued from the time when our President, Sir Weldon, was Deputy Chief Medical Officer at the Ministry. It was Sir Weldon who was the moving force in the adoption of the green Haemophilia Card scheme, which has proved such a boon to so many sufferers.

The Society has recently had discussions with officials at the Ministry of Health in regard to the availability of Human Anti-Haemophilia Globulin in treatments; in this matter the Society is much concerned. There is also the problem of the suitability of the invalid tricycles. The latter has been the subject of constructive criticism from some Members. It is hoped to raise the matter in official circles as soon as a favourable opportunity arises.

I am pleased to report that the Ministry of Health has recently appointed Dr. Archibald, one of their Senior Medical Officers who, in the Ministry's own words, "will correlate, on the medical side, planning concerning the diagnosis, treatment and welfare of haemophiliacs". This appointment is a most welcome one and I am happy to say that Dr. Archibald has accepted the invitation to serve as an observer on our Council, with, I am sure, great benefit accruing both to the Society, the Ministry of Health, and those the Society serves.

Hospital to investigate haemophilia and other coagulation disorders. She has the support of the Medical Research Council who have awarded her a grant to enable her to prepare a report on the medical and educational problems of haemophilic children attending hospitals in and around London: a survey that will be carried out in co-operation with the Ministry of Education and the hospitals concerned. A very important and comprehensive survey this will be and in the main it will be on a personal visit basis. The Society is of the opinion that this report, when it comes to be written, might well result in better medical and educational facilities being made available for children with haemophilia, throughout the country, during, what must be, the most important period of their lives.

After due consideration and then, I might say, most willingly, the Committee has promised Dr. Dormandy its full support. In this connection many of our Members will shortly be approached to ascertain their willingness to allow the Society to give their names and addresses to Dr. Dormandy so that her Social Worker, Mrs. Britten (who incidentally is the mother of a haemophiliac), can arrange to visit them.

The Society has agreed also to give financial support to Dr. Dormandy's project, which will be known as "The Haemophilia Social Service and Research Unit". The Council has agreed to donate, from the Society's Research Fund, the sum of £1,000, part to be used in meeting one of the Doctor's most pressing needs, that of working space. As a means to this end a 35 ft. caravan has been obtained. The Royal Free Hospital were unfortunately unable to help in this direction as they themselves are in the throes of an extensive rebuilding scheme. Dr. Dormandy's great enthusiasm and enterprise has however encouraged the authorities at The Royal Free to approve the caravan being placed in the grounds of the hospital in close proximity to her laboratory; indeed I understand it has actually been installed and is ready for occupation.

The Society intends to launch an appeal to still further help this scheme. In the first instance endeavour will be made to interest certain charitable trusts and organisations in the project, in the hope that it may be possible in this way to raise the sum required to equip and staff the unit, estimated to be in the region of some £10,000. There is great optimism within the Society that, with the active assistance of its Members, this can be done. Your wholehearted support is asked for.

ANNUAL REPORT FOR 1964

A survey of the year 1964 shows that the Committee, in administering the affairs of the Society, continues to be faced with all the old problems and with many new ones, too. Yet there also appears, on reading through the minutes, a greater sense of confidence in the Committee's ability to confront those problems; a confidence which must have come from the mounting years of experience, from the growing funds it has behind it, and from the increasing goodwill and regard for the Society which is now to be found in so many quarters.

The records show innumerable examples of how members continue to turn to the Society for help in their difficulties, and in extending its help to those members, after due deliberation yet with expedition, the Committee is surely carrying out one of the most important aims of the Society.

Financial help has been given to many members, and it has often been coupled with practical help and advice to do with such affairs of everyday life as house repairs, clothing, home tuition and the installation of a telephone. This last, and some other special cases, have been tackled in conjunction with other charitable organisations, a practice of joint action and responsibility which is wholly to be welcomed. Other kinds of help and advice of a useful and positive nature have been given in plenty, either by letter or by personal visits from one of the Officers or Members of the Committee, or the Society's Honorary Medical Social Worker or its Medical Adviser. There have been problems of work, of housing, of insurance, of education, and in one case the path was smoothed for the provision of a wheel chair for a member who looked like being disappointed.

Problems have been dealt with not only in individual cases, but on a general plane. For example, in a considerable volume of correspondence addressed to the Ministry of Health, the Society took part in an enquiry on the suitability and value of the invalid carriages provided for disabled people. This matter is still being pursued. Again, in another

very important field, shortages have appeared in the supply of materials necessary in the treatment of Haemophilia. Our enquiries have been received with interest and sympathy, and we may hope that good will come of them.

The varying medical treatment accorded to haemophiliacs has been, during the year, brought to the notice of the Society. The Officers did what seemed right to ensure the best use of the facilities provided by the Health Service and the Ministry of Health. Because these facilities are not as widely known, or as well understood as one could hope, troubles occur from time to time, with disquieting results to haemophiliacs. Success does not always follow the Committee's efforts, for circumstances sometimes seem to be beyond the power of anybody to change them. Nevertheless, the Committee always tries, and is rewarded sometimes by achieving some happy arrangement, and nearly always by finding that the Society's views are willingly considered. It is. worth noting that its views are often sought by other organisations and authorities before the Committee offers them, and it is surely refreshing to note that the practice of writing to one's M.P. has been reversed by an M.P. taking the initiative and writing to us. His enquiry was dealt with promptly. Our advice has also been sought by students of Nursing and Physiotherapy, by teachers and by research workers in other fields.

Personal contacts have been kept much alive with other organisations and authorities. Four members of the Committee paid a long and most interesting visit to the Lord Mayor Treloar College at Alton, a residential school for disabled boys of secondary school age. The School has a high proportion of haemophiliacs in good spirits and all owing very much to the wisdom and kindness of the Principal. The Committee thought it appropriate to ask to be allowed to present an annual prize to the school, and this has been welcomed. The Chairman attended a meeting of the World Federation of Haemophilia, in Amsterdam, where he was able to meet some thirty representatives of other Societies from all parts of the world. The meeting was presided over by Professor Van Creveld who also arranged a rewarding

In the main, I suppose, it is money and more money that is needed in order to finance the many undertakings already started and to enter new fields of usefulness: and the Committee has in mind to make a special appeal for one very important project, to which I will refer later; may this meet with the success it deserves.

May I make one personal observation—it is to say how impressed I have been with, what I might term, the family spirit that prevails throughout the Society and enters into your many undertakings. I have no doubt that this counts for many of your successes, in the Groups, as well as at Headquarters.

There are one or two matters to which I would wish to make special reference. The first is the need in this country for a Residential School for haemophiliacs between the ages of 5 and 11 years, preferably situated near one of the major Haemophilia Reference Centres, such as exists at Oxford. I understand that such a school exists in France with which the Haemophilia Society of France is closely associated; from reports that the Committee have had, it is a great success.

In Amsterdam a school is attached to the Haemophilia Clinic. What an advantage it must be to the scholars to have this special educational need as well as, in the immediate vicinity, expert medical and surgical advice, should any emergency arise. May one express the hope that ere long something similar will be available in this country.

Some amongst you will have helped in the initial enquiry the Society made on the subject of education. From this survey one learns of the proportion of haemophilic children attending normal primary schools, physically handicapped schools, boarding schools, etc. In the course of this enquiry some parents wrote giving their reactions to the type of education their children were receiving. These opinions, it was thought, would be of interest to the Ministry of Education and were accordingly passed on to that authority.

Whilst the subject of a Residential School was under discussion, your Committee was approached by Dr. Katharine Dormandy of The Royal Free Hospital, a lady whom many of us know very well since she was attached to this hospital (The Hospital for Sick Children), and worked in the laboratories with the Director of the Department of Haematology, Dr. Hardisty. Dr. Dormandy is deeply interested in the subject of haemophilia and is endeavouring to establish a unit at The Royal Free

ADDRESS given at the Annual General Meeting of the Haemophilia Society on April 25th, 1965, by

H. F. Rutherford, O.B.E., F.H.A.,

Formerly the House Governor of The Hospital for Sick Children, Great Ormond Street, London, W.C.1,

Vice-President of the Haemophilia Society.

Mr. Chairman, Ladies and Gentlemen,

Firstly may I say what a privilege it is, for me, to be asked to speak at this Annual General Meeting. You will, I hope, forgive any shortcomings—I undertook to do this at very short notice, somewhat unaware of the responsibilities it involved and its immense ramifications.

I propose to start, where most would end, by acknowledging most sincerely, the magnificent services rendered throughout the year by all Members of the Committee, under the expert guidance of your Honorary Chairman, Mr. J. R. Hunter, and Mr. P. H. Morris, the Vice-Chairman. Special thanks are, I am sure you will all agree, due to Mr. Polton for all that he has done, while assisted, very willingly, by Mrs. Hawkins, who is leaving us, and by Mrs. Watson who is replacing her in the office. One must not forget, of course, our Honorary Treasurer, Mr. Cooper, who so generously loosens the purse strings when need arises.

Now for a few moments let us look at the year's work and make reference to our plans for the future.

Many of you will have read, with interest, the Annual Report. I have had an opportunity of perusing the final draft and frankly, I am amazed to learn of what has been done. A healthy, progressive, virile and efficient organisation is this, built clearly on a very sound foundation—may it long prosper and progress; it certainly deserves, and intends to do so.

It is not for me to refer to everything that has been accomplished throughout the year for it is set out excellently in the report which can be studied in the quiet of one's home.

and illuminating visit to his Haemophilia Clinic, recently opened by Her Majesty the Queen of the Netherlands.

We have also been busy distributing the Society's literature through the Haemophilia Reference Centres, who so kindly offered, in this matter and in others, to help us. This literature included the Annual Report for 1963 and, most important of all, the address given by Professor Squire at the Annual General Meeting in Birmingham at which it was presented. The literature also included a revised leaflet on Haemophilia and the Society, some 3,000 copies of which went to the Haemophilia Centres alone and at their request. Hundreds of copies have been sent, in addition, to certain hospitals, to Nursing Associations, to Hospital Almoners now-renamed Medical Social Workers, and to branches of the National Council of Social Service, which covers the Citizens' Advice Bureaux, and to many other places where it seemed a useful purpose was to be served. Five Hundred copies were sent to one of the Chapters of the Haemophilia Foundation of the U.S.A. Undoubtedly haemophilia has become a less closed book, and the Society a less obscure group, than used to be so, not many years ago.

Other activities have been pursued. The stamp collecting circle, organised by two haemophiliac members, is already flourishing and has fifty names on its list. A special fund was set aside for helping to provide holidays, in conjunction with the Red Cross, and last summer ten haemophiliac members benefited. The discs to be worn by haemophiliacs has aroused much interest-enquiries came from Medical Officers of Health and from the Medical Press—and three hundred have been issued during the year to holders of green cards. Lapel badges bearing the Society's emblem have been made and a large number have already been sold. To answer the enquiry which it is hoped the badge will elicit, there has been printed a small card which gives the answer clearly and briefly and which fits nicely into a small pocket. Two useful home nursing aids, bed cradles and ice packs, have been made available and have been taken by a number of members. Towards the end of the year, two ladies among our membership undertook a trial scheme for the sale of Christmas cards, as

a result of which nearly £50 flowed into our funds. At the very end of the year the Christmas Party was held, a piece of hard organising and work for the Committee Members and the Ladies, which again was rewarded by the obvious enjoyment brought to so many people, particularly our young members. Eighty-three Christmas parcels were sent this year, a considerable increase over the number sent in 1963.

As shown by the audited accounts, the finances of the Society continue to be sound and soundly administered. Two ways in which they have been augmented deserve very special mention. On the 23rd of August, 1964, Lady Gaitskill broadcast in the Week's Good Cause an appeal for the Society. As a result of her kindness and the preparatory work put into this appeal the Society received £588 15s. 5d. by the end of the year. Another most interesting and encouraging event was a recommendation made by the Chairman of Barclays Bank, to whom had been entrusted the disposal of a charitable bequest. As a result of this recommendation the Society received an addition to its funds of £1,500. It is appropriate here to record that the Society was, during the year, re-registered under the Charities Act 1960, and we may well feel that these events have set upon the Society the seal of recognition as the lay organisation and source of information for Haemophilia.

In 1964 the first steps were taken in some of the wider projects to which the last Annual Report made reference. We anticipate that, for these, our funds will be used on a scale not possible before. For example, the Committee decided to help in an enquiry, the purpose of which is to show what still needs to be done for haemophiliacs in spite of all the services which are already provided. This enquiry is being conducted in London by one of our medical friends and is principally supported by the Medical Research Council. The Society became actively interested in an even more ambitious project which was to set up a haemophilia social service and research unit. The project owed its beginnings to the enterprise of other individuals and authorities; nevertheless, the support of the Society was sought and welcomed

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xed Income & Expenditure Accounts, and have obtained if, were necessary for the purposes of the audit. In my one hotors, the and the Society's Balance Sheet and sone bolos, the society is Balance Sheet and all and the Income and Expenditure Accounts give a true that date.

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£ s. d.	as Grants) 20 0 0	1	: :			date—C/F	17.5	Y .
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when given. It should in time make a great contribution to the treatment of Haemophilia. The possibility of a special residential school for Haemophiliac children of primary school age has also engaged the attention of the Committee and Council. The Society will be, or already is, financially, practically, fully and intimately concerned with all of these projects. In 1964 they have been getting under way and they will not function fully, if all goes well, until 1965 and beyond. We may therefore hope that they will provide fuller material for future Annual Reports.

The work of the Groups throughout the country is more fully dealt with in their own Annual General Meetings and reports than is possible with justice here. By the nature of a Regional Group it is in caring for the individual that the most valuable work is done. Visits and help to members, parties, outings—in one case an exhibition of work—all these and many other things have been arranged. The work of the Officers and Committees of all our Groups is surely deserving of high praise and a wholehearted tribute.

The Annual Report for 1963 ended by speaking of the work of the Officers and Committee in holding the Society together and in keeping it on its proper course. During 1964 the responsibilities placed upon them have become far greater because of the very possibilities opened up by the growth during recent years of the Society's stature. The Society has moved and is still moving into fields which are new to it; and while its old aims are never forgotten, the ends which it must pursue are multiplying with the means at its disposal. This report can justly conclude by recording the Society's gratitude to those who are working for these ends.

Finally a special "thank you" to all members and supporters who by their practical interest and participation in the affair of the Haemophilia Society are enabling it to give ever increasing help to haemophiliacs.

INCOME & EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31st DECEMBER, 1964. GENERAL FUND

EXPENDITURE £	E s. d.	£ s. d.			INCOME £ s. d. £ s. d.
	11 17 5	70 0 0	•		Subscriptions 143 0 0
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	12 18 9 16 10 5	16 8 4	$\binom{1}{2}$	$\binom{n}{n}$	Less: Transfer to Research Fund 400 0 0 Transfer to
Office Salaries & State Insurance		273 6 2			Benefit Fund 350 0 0 750 0 0 1,624 15 7
		32 14 3 34 10 10			Collections (Gross) 48 6 9
Printing & Stationery		271 18 6			Grant—L.C.C. Sunday Cinema Fund 60 0 0
		296 13 9		Ż	B.B.C. "Week's Good Cause" Appeal (Gross) 588 15 5
~~		79 5 0 27 15 10			Social Functions, etc 168 4 6 *Less: Cost of Draw
Gifts & Presentations		1 11 9			Tickets 9 16 0
Subscriptions to Affiliated Societie Auditors Honorarium	es	4 9 0 16 16 0		•	Cost of Posters' 2 5 7 Cost of S'dry Items 14 6 12 16 1 155 8 5
Miscellaneous Expenses		34 17 9		•	
		81 3 0 129 0 0			4 4 7
		21 0 0			Annual Draw 406 8 3 Less: Cost of Tkts. 22 1 0
Identity Discs—supply of and engr	aving	105 4 9			Prize Money 19 7 6
	5 15 8				Transfer to Holiday Fund 200 0 0 241 8 6 164 19 9
Less: Various Donations, etc. 3	5 2 0	40 13 8			Football Treble Competition 358 2 6
					Add: Receipts in Advance
DEPRECIATION					in 1963 B/D 135 8 1
Office Equipment 1	1 0 0			5	Less: Cost of Cards 28 5 9
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BALANCE, being Excess of			**		Christmas Cards—sale of (Gross) 47 15 2
,	,,,	2,001 2 1		•	Canadian Booklet—"Haemophilia Today"— sale of surplus 1 0 0
					Interest on Defence Bonds 18 4 10
					Interest on Deposit Account 42 13 8
	£	3,568 13 1			£3,568 13 1
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