
MYELOPATHY.ORG

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2020

MYELOPATHY.ORG

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**REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 30 JUNE 2020**

Trustees

Dr Mark Kotter
Lady Julia K H Carter of Coles
Mrs Weslie R Janeway
Ms Helen J Wood (appointed 7 November 2019)
Dr Johann Graggaber
Ms Carol Sun (appointed 27 February 2020)
Mr David Townshend (appointed 27 February 2020)

Charity registered number

1178673

Principal office

Lakin Rose
Pioneer House
Vision Park
Histon
Cambridge
CB24 9NL

Independent examiners

Lakin Rose Limited
Pioneer House
Vision Park
Histon
Cambridge
CB24 9NL

**TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2020**

The Trustees present their annual report together with the financial statements of the Myelopathy.org for the year 1 July 2019 to 30 June 2020.

Objectives and activities

a. Policies and objectives

To advance health and education in all aspects of Myelopathy in particular but not exclusively by:

1. Supporting and funding scientific research into all aspects of Myelopathy and ensuring the useful results of such research are publicly disseminated.
2. Raising awareness and understanding of the condition in all its forms including sharing current research and healthcare information.
3. Supporting and promoting improved physical and mental outcomes for patients including establishing support for patients, carers and health professionals.

In setting objectives and planning for activities, the Trustees have given due consideration to general guidance published by the Charity Commission relating to public benefit, including the guidance 'Public benefit: running a charity (PB2)'.

b. Main activities undertaken to further the charity's purposes for the public benefit

(1) Research

The following section summarises the projects that Myelopathy.org has been involved in which further our first charitable aim, to support research in the field of DCM. Below we have included further explanations of each of the projects which in each case are being done to better understand the condition and the best ways to treat it in order to improve the lives of the people affected by it. We believe that this is for the future public benefit and fulfils our obligations as trustees.

AO Spine RECODE DCM

Myelopathy.org is a partner in AO Spine RECODE DCM an international consensus initiative to involve people with DCM alongside healthcare professionals, in the design and direction of DCM research. Following the James Lind Alliance methodology, 3404 research ideas were gathered from 429 individuals (231 surgeons, 99 other healthcare professionals (HCP), 99 people with DCM or their supporters) using an online survey from around the world. These were refined to produce 74 unanswered summary questions, which were prioritised in a second survey by 417 participants (214 Surgeons, 310 health care professionals, 107 people with DCM or their supporters). The top 7 unique questions per stakeholder group (20 questions) and a further 6 questions selected by the AO Spine RECODE-DCM Steering Committee, entered a face-to-face consensus meeting in New York in November 2019. This was attended by 25 individuals (7 surgeons, 6 HCP, 11 people with DCM and 1 supporter).

Myelopathy.org co-founders Dr Mark Kotter, Dr Ben Davies and Iwan Sadler together with other members of the Myelopathy.org support group attended this meeting.

The top 10 priorities for research were agreed.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2020**

Objectives and activities (continued)

The Top Ten Research Priorities

	Short Title	Full Priority Wording
1	Raising Awareness	What strategies can increase awareness and understanding of DCM amongst healthcare professionals and the public? Can these strategies help improve timely diagnosis and management of DCM?
2	Natural History	What is the natural history of DCM? What is the relationship between DCM and asymptomatic spinal cord compression or canal stenosis? What factors influence the natural history of the disease?
3	Diagnostic Criteria	What are the diagnostic criteria of DCM? What is the role of imaging and when should imaging be used in the assessment of DCM?
4	Assessment and Monitoring	What assessment tools can be used to evaluate functional impairment, disability and quality of life in people with DCM? What instruments, tools or methods can be used or developed to monitor people with DCM for disease progression or improvement either before or after surgical treatment?
5	Pathophysiology	What is the pathophysiology of DCM? What are the mechanisms of neurological injury and the molecular and anatomical consequences?
6	Rehabilitation	What is the role of rehabilitation following surgery for DCM? Can structured postoperative rehabilitation improve outcome following surgery for DCM? What are the most effective strategies?
7	Novel Therapies	Can novel therapies, including stem-cell, gene, pharmacological and neuroprotective therapies, improve the health and wellbeing of people living with DCM and slow down disease progression?
8	Socio-economic Impact	What is the socio-economic impact of DCM? (<i>The financial impact of living with DCM to the individual, their supporters and society as a whole</i>)
9	Imaging Techniques	What is the role of dynamic or novel imaging techniques and neurophysiology in the assessment of DCM?
10	Individualising Surgery	Are there clinical and imaging factors that can help a surgeon select who should undergo surgical decompression in the setting of DCM? At what stage of the disease is surgery the preferred management strategy?

The priorities go beyond the current focus of research on surgery, including aspects of diagnosis, rehabilitation, long-term care, pre-clinical science, health economics, awareness and education. Inclusion of education and awareness represent a clear example of how Myelopathy.org has been able to champion the voice of people living with conditions in participation: (1) These emerged as the number 1 priority but were only ranked 25th by other healthcare professionals and 45th by surgeons after the second survey. (2) A research question on education and awareness has never previously been a research priority in DCM.

Owing to COVID19, dissemination plans for the research priorities were altered and the findings were released at an open access webinar in May 2020, attended live by 300 people from around the world, and watched a further 249 times since.

AO Spine RECODE DCM is ongoing, with remaining objectives of developing a minimum dataset for research and agreeing the name. This will complete in 2020/21. Additionally, an active dissemination process is underway to ensure the scientific community is now aware of what to research. These research priorities will direct future Myelopathy.org funding and strategies.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2020**

Objectives and activities (continued)

To continue the work done by RECODE DCM in identifying the top ten research priorities, Myelopathy.org is committed to continuing the pursuit of additional patient directed research for public benefit and will continue to work with **'SMART-Research'** (**S**uffers with **M**yelopathy **A**sks / **A**pproved **R**esearchers **T**o **R**esearch). This is a focus group of DCM sufferers and their supporters, who provide peer-review for external proposals, or develop research questions of their own.

RECEDE Myelopathy [Regeneration in Cervical Degenerative Myelopathy] (University of Cambridge and National Institute for Health Research)

Phase III, double blind, placebo randomised controlled efficacy study of Ibudilast (a medicine) as an additional therapy to decompressive surgery (the gold standard treatment) for DCM. Ibudilast is a medicine currently under investigation for treatment of Multiple Sclerosis, Motoneuron Disease (ALS) and Brain Tumours.

Myelopathy.org continues to support this clinical research trial. Ethical approval of the trial was obtained in early 2020 but the COVID 19 pandemic has resulted in a delay to its implementation.

(2) Awareness

This section describes the activities of Myelopathy.org has been involved in that further our second charitable aim, to raise awareness of DCM.

Myelopathy Matters PodCasts

Myelopathy Matters is a PodCast series produced by Myelopathy.org. The aim of the PodCast is to provide contemporary information on DCM, to educate listeners on the latest news and views both from healthcare professionals and scientists, but also people living with DCM. The PodCast aims to help Myelopathy.org reach new and international audiences, of both healthcare professionals, scientists and people living with DCM.

PodCasts are a popular medium at present, and well suited for listeners with DCM, who may become uncomfortable sitting watching a screen for example.

Patient education

Following feed-back from the Myelopathy.org support group, this year we have started work on producing a series of patient information handouts (to be made available in both physical and digital form) to cover the three separate stages of the DCM journey, namely diagnosis, pre-surgery and post-surgery. These are being produced in collaboration with Dr Rory Murphy, a neurosurgeon and assistant professor at the Barrow Neurological Institute at Barrow Brain and Spine, Arizona, USA. These handouts will both help raise awareness of the different stages of the DCM journey to people with DCM and also offer them support.

Google Ads

As part of our aim to raise awareness of DCM Myelopathy.org applied for a Google Ad Grant from the Google Ad Grants Online Marketing Challenge. This was a competitive process and Myelopathy.org was successful in being awarded a grant.

The Online Marketing Challenge is a unique opportunity for students to get real-world experience creating and executing online marketing campaigns for charities using a \$10,000 USD monthly budget of in-kind Google Ads advertising credit through the Google Ad Grants program.

The student team created Google Ads campaigns that focused on two key objectives in different geographical locations:

1. targeting aware groups
2. targeting non-aware groups

The campaigns increased traffic to our website and lowered our high bounce rate by 10% by sending users to relevant landing pages. The aware campaign performed well and had the highest number of conversions. The campaigns in different geographical locations performed way above our click-through-rate expectation.

The student team completed a Post-Campaign Analysis and made recommendations to help us continue to thrive online.

We are working on further developing our website and marketing efforts to help implement their recommendations to help us raise awareness and target the people we want to reach.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2020**

Objectives and activities (continued)

UK Points of Light

Every weekday the Prime Minister recognises an inspirational volunteer with the Daily Point of Light award. Dr Mark Kotter, Dr Benjamin Davies and Iwan Sadler, the co-founders of Myelopathy.org were the Points of Light recipients on 26 February 2020 in recognition of their work promoting research and awareness of DCM and creating a support community for people with DCM. They each received a personal letter of congratulations from Prime Minister Boris Johnson. This national recognition of Myelopathy.org has further helped raise awareness of DCM to a wider audience.

Health Economics

Myelopathy.org commissioned a report in 2020 on the socio-economic impact of DCM in the UK. It is intended that the results of this report will be published in early 2021 and made available via the Myelopathy.org website. The report will inform future research into the socio-economic impact of DCM both at an individual and societal level. This report will further help raise awareness of DCM and the impact it has.

(3) Support

Our Myelopathy Support page on Facebook continues to grow and now has over 3,000 followers. Myelopathy.org also runs an on-line support group on Facebook which has approximately 1500 members. Members of the DCM community run a peer mentoring programme where people with significant lived experience of DCM provide information and support to others during different stages of their DCM journey.

Both groups are run by Iwan Sadler, co-founder of Myelopathy.org and a person with DCM.

The Myelopathy Matters PodCast series offers the DCM community an additional platform to learn about what is happening at Myelopathy.org. The series includes information on research projects, interviews with leading healthcare professionals in the field of DCM and information from people with DCM. This helps to fulfil our objective of supporting and improving the physical and mental outcomes for people with DCM by providing a supportive and informative information source.

Achievements and performance

a. Review of activities

Below is a brief summary of the main achievements of Myelopathy.org this year

- We have been a partner in RECODE-DCM which has now identified the Top 10 research priorities for DCM
- Our co-founders Dr Mark Kotter, Dr Ben Davies and Iwan Sadler, together with other members of the Myelopathy.org Support Group attended the consensus meeting of RECODE-DCM in New York in November 2019. They were able to inform the identification of the Top 10 Research Priorities and make the voice of people with DCM heard.
- We have launched a PodCast series to better inform our community about the work of Myelopathy.org
- We have appointed a new trustee to the Board of Myelopathy.org. Helen Wood is a former solicitor and has a background in medical ethics and law.
- Our co-founders Dr Mark Kotter, Dr Ben Davies and Iwan Sadler were awarded the Prime Minister's Points of Light award which has highlighted the work of Myelopathy.org to a nationwide audience.
- 2020 saw the start of COVID-19 global pandemic and this highlighted the need for Myelopathy.org to continue its work to inform and support our community. Our digital platform has enabled us to continue this work seamlessly but has highlighted the need to improve how we do this to best support our community who has been hard hit by the restrictions to much of normal life.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2020**

Financial review

a. Going concern

After making appropriate enquiries, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. For this reason, they continue to adopt the going concern basis in preparing the financial statements. Further details regarding the adoption of the going concern basis can be found in the accounting policies.

b. Reserves policy

At present Myelopathy.org has minimal annual liabilities. Consequently, and based on the limited annual income, it is felt that a reserve fund is not required nor possible at this time.

This position will be reviewed annually by the Trustees.

Structure, governance and management

a. Constitution

Myelopathy.org is a registered charity, number 1178673, and was incorporated on 6 June 2018.

b. Methods of appointment or election of Trustees

The management of the charity is the responsibility of the Trustees who are elected and co-opted under the terms of the Constitution.

c. Financial risk management

The Trustees have assessed the major risks to which the charity is exposed, in particular those related to the operations and finances of the charity, and are satisfied that systems and procedures are in place to mitigate exposure to the major risks.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2020**

Statement of Trustees' responsibilities

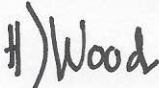
The Trustees are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles of the Charities SORP (FRS 102);
- make judgments and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards (FRS 102) have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the Trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the members of the board of Trustees on 14.4.21 and signed on their behalf by:



Ms Helen J Wood
Trustee

**INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 30 JUNE 2020**

Independent examiner's report to the Trustees of Myelopathy.org ('the charity')

We report to the charity Trustees on our examination of the accounts of the charity for the year ended 30 June 2020.

Responsibilities and basis of report

As the Trustees of the charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the 2011 Act').

We report in respect of our examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out our examination we have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Your attention is drawn to the fact that the charity has prepared the accounts in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has been withdrawn.

We understand that this has been done in order for the accounts to provide a true and fair view in accordance with the Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

We have completed our examination. We confirm that no matters have come to our attention in connection with the examination giving us cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the 2011 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

We have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

This report is made solely to the charity's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our work has been undertaken so that we might state to the charity's Trustees those matters we are required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's Trustees as a body, for our work or for this report.

Signed:

Dated: 15 April 2021

Carla Barnes FCCA

Lakin Rose Limited

Pioneer House, Vision Park, Histon, CB24 9NL

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2020

	Note	Unrestricted funds 2020 £	Total funds 2020 £	Total funds 2019 £
Income from:				
Donations	3	26,001	26,001	16,812
Charitable activities	4	7,727	7,727	-
Total income		33,728	33,728	16,812
Expenditure on:				
Charitable activities		29,870	29,870	12,177
Total expenditure		29,870	29,870	12,177
Net movement in funds		3,858	3,858	4,635
Reconciliation of funds:				
Total funds brought forward		4,635	4,635	-
Net movement in funds		3,858	3,858	4,635
Total funds carried forward		8,493	8,493	4,635

The Statement of financial activities includes all gains and losses recognised in the year.

The notes on pages 11 to 15 form part of these financial statements.

MYELOPATHY.ORG

BALANCE SHEET
AS AT 30 JUNE 2020

	Note	2020 £	2019 £
Current assets			
Debtors	8	2,587	1,563
Cash at bank and in hand		6,656	4,146
		<u>9,243</u>	<u>5,709</u>
Creditors: amounts falling due within one year	9	(750)	(1,074)
Net current assets		<u>8,493</u>	<u>4,635</u>
Total assets less current liabilities		<u>8,493</u>	<u>4,635</u>
Total net assets		<u>8,493</u>	<u>4,635</u>
Charity funds			
Restricted funds	10	-	-
Unrestricted funds	10	8,493	4,635
Total funds		<u>8,493</u>	<u>4,635</u>

The financial statements were approved and authorised for issue by the Trustees on 14 April 2021 and signed on their behalf by:

H) Wood

Ms Helen J Wood
Trustee

The notes on pages 11 to 15 form part of these financial statements.

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2020**

1. General information

The charity is a charitable incorporated organisation (CIO). The charity's address is c/o Lakin Rose, Pioneer House, Vision Park, Histon, Cambridge, CB24 9NL.

2. Accounting policies

2.1 Basis of preparation of financial statements

The financial statements have been prepared in accordance with the Charities SORP (FRS 102) - Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair' view. This departure has involved following the Charities SORP (FRS 102) published in October 2019 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

Myelopathy.org meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

2.2 Income

All income is recognised once the charity has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

2.3 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use.

Expenditure on charitable activities is incurred on directly undertaking the activities which further the charity's objectives, as well as any associated support costs.

All expenditure is inclusive of irrecoverable VAT.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2020

2. Accounting policies (continued)

2.4 Liabilities and provisions

Liabilities are recognised when there is an obligation at the balance sheet date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably.

Liabilities are recognised at the amount that the charity anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

Provisions are measured at the best estimate of the amounts required to settle the obligation. Where the effect of the time value of money is material, the provision is based on the present value of those amounts, discounted at the pre-tax discount rate that reflects the risks specific to the liability. The unwinding of the discount is recognised in the statement of financial activities as a finance cost.

2.5 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

3. Income from donations

	Unrestricted funds 2020 £	Total funds 2020 £	<i>Total funds 2019 £</i>
Donations	26,001	26,001	16,812

4. Income from charitable activities

	Unrestricted funds 2020 £	Total funds 2020 £	<i>Total funds 2019 £</i>
Research services	7,727	7,727	-

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2020

5. Analysis of expenditure by activities

	Activities undertaken directly 2020 £	Support costs 2020 £	Total funds 2020 £	Total funds 2019 £
Charitable activities	8,424	21,446	29,870	12,177
<i>Total 2019</i>	10,686	1,491	12,177	

Analysis of direct costs

	Charitable activities 2020 £	Total funds 2020 £	Total funds 2019 £
Conference expenses (BASS)	-	-	927
Conference expenses (SBNS)	-	-	235
Conference expenses (HoL)	-	-	5,197
Conference expenses (S Forum)	-	-	4,327
Education	3,559	3,559	-
Research	4,865	4,865	-
	8,424	8,424	10,686

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2020

5. Analysis of expenditure by activities (continued)

Analysis of support costs

	Charitable activities 2020 £	Total funds 2020 £	Total funds 2019 £
General office expenses	1,020	1,020	371
Computer expenses	647	647	10
Insurance	248	248	-
Subscriptions	157	157	50
Travel and subsistence	182	182	-
Grant funded Google advertisements	18,632	18,632	-
Governance costs	560	560	1,060
	21,446	21,446	1,491
	21,446	21,446	1,491

6. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £750 (2019 - £ -).

7. Trustees' remuneration and expenses

During the year ended 30 June 2020, no Trustees received any remuneration or other benefits (2019 - £NIL).

During the year ended 30 June 2020, no Trustee expenses have been incurred (2019 - £NIL).

8. Debtors

	2020 £	2019 £
Prepayments and accrued income	149	-
Tax recoverable	2,438	1,563
	2,587	1,563
	2,587	1,563

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2020

9. Creditors: Amounts falling due within one year

	2020 £	2019 £
Accruals and deferred income	<u>750</u>	<u>1,074</u>

10. Statement of funds

Statement of funds - current year

	Balance at 1 July 2019 £	Income £	Expenditure £	Balance at 30 June 2020 £
Unrestricted funds				
General Funds	<u>4,635</u>	<u>15,096</u>	<u>(11,238)</u>	<u>8,493</u>

Statement of funds - prior year

		<i>Income</i> £	<i>Expenditure</i> £	<i>Balance at</i> <i>30 June</i> <i>2019</i> £
Unrestricted funds				
General Funds		<u>16,812</u>	<u>(12,177)</u>	<u>4,635</u>