

Open the Windows: Poetry & Medicine

*Rebecca Goss, Denise Bundred
& Chris Davies with Beth Allen*



National Aspergillosis Centre,
UHSM, Manchester

Open the Windows: Poetry & Medicine

Introduction

The National Aspergillosis Centre (NAC) is delighted to present this event in partnership with Manchester Literature Festival and Manchester Museum.

Based at University Hospital of South Manchester, the National Aspergillosis Centre (NAC) treats patients with fungal disease, usually of the lungs.

Rebecca Goss's newborn daughter Ella was diagnosed with a heart condition at the hospital where Denise Bundred worked. However, they only met later as poets, writing about their respective experiences as mother/patient and doctor.

This is their first joint reading, which also features music celebrating 'breath' commissioned from Chris Davies and Beth Allen.

Thank you for coming!



Rebecca Goss & Denise Bundred



Rebecca Goss grew up in Suffolk and recently returned to live in the county, after spending many years in Liverpool. Her acclaimed second collection, *Her Birth*, shortlisted for The Forward Prize for Best Collection of Poetry 2013, begins with Ella's birth, her short life and her death, and ends with the joys and complexities that accompany the birth of another child.



Denise Bundred trained as a paediatrician in Cape Town, South Africa, and as a paediatric cardiologist in Liverpool where she worked until she retired. An MA in Writing at Liverpool John Moores University persuaded her to write poetry. She was highly commended in the 2012 & 2013 Hippocrates Prize.

Chris Davies & Beth Allen



Freelance musician/
performer **Chris Davies** works
mainly with visual theatre and
dance, and is interested in music as
a means of promoting a sense of
well-being. At present, Chris is
working with people living
with dementia and their
companions on *Fleeting Moments*,
a collaboration between
Chaturangan Dance Company,
Bluecoat and Liverpool
Hope University.



Beth Allen, creative voice
specialist and *Sacred Sounds*
choir director for John Tavener
at this year's Manchester
International Festival, says that
breath is at the core of her work.
Beth trained as an Opera Singer
at the Royal Scottish Academy,
then as a Music Therapist at
Guildhall and as Voice Specialist
at Central School of Speech and
Drama. She works with people of
all ages.

Poetry at the NAC

Why?



We use creative writing as a means to foster new relationships and new types of communication between NAC staff and patients & their carers.

How?



Our Writer-in-Residence Caroline Hawkridge has encouraged writing by patients, carers and staff during our monthly support groups and via our global online groups on Facebook and Yahoo! Her visits also led us to consider hosting this event to help raise awareness of Aspergillosis and the problems it can cause.

Caroline wrote women's health books before doing an MA in Creative Writing at Manchester Metropolitan University (MMU).

Fungal friends

Things have been wrong for quite some time.
Some days I struggle, some days I'm fine.
I'm breathless, tired and ask for tests
To see what is happening with my chest.
They tell me I have some fungal spores
But do not understand the cause.
So I ask around and make a fuss
And discover a fungus called *Aspergillus*.

I use the clever search engine to find out the facts,
Which directs me to experts at a place called "NAC".
I ask my doc if he will send me there
Though still want him to share my care.
He agrees it would be nice to be helped
To unravel the mystery that has developed.
So he sends me off to visit the team
And asks me to tell him what knowledge I glean.

I meet the doc and tell my tale
Of how my strength continues to fail.
Fit as a fiddle I used to be,
Now I have trouble making tea.
My chest is tight and I cough a lot.
The nurse then tells me to spit in a pot,
For some special test to see what it grows,
Funny-named fungus that few of us knows.

What did I do in my fitter days?
Cos now they are spent having frequent x-rays.

Blood tests are taken for more special tests,
Which leaves my arm in need of a rest.
But although I feel like I want to curse
I would be lost without my specialist nurse.

The doc keeps an eye on my CT scan,
To check and see if my cavity has gone.
He sends me away with a cocktail of medicine
And they ask me to fill their questionnaire in.

At the end of the month I can meet others like me
To share our experiences over a nice cup of tea.
Speakers and staff tell us the latest news,
And our friends on the web are asked their views.
It's good to know that fungus is widely debated,
And makes my family and me feel less isolated.
So while I know I have to keep coming back,
I'm so glad to be part of the place called "NAC".

*Chris Harris,
National Aspergillosis Centre Manager.*

Mouldy woes

It was soft and fresh when it was sold
But now it shows some signs of mould.
Like a green-eyed monster staring at me,
My breakfast is off it's clear to see.

And that's not the only place
It dares to show its freaky face.
It creeps along the bathroom wall
Competing with the dust that falls.
A dark and grimy shadow is cast,
Like some creepy ghost from the past.

I keep a neat and tidy house I do,
Yet still there is evidence of mildew.
I could blame it on the environment
For the reason it remains present.

But there's no need to be filled with dread
When it only appears upon my bread,
As it's really only a minor sin
When he's lurking inside my bread bin.

It's the one that hovers around my skirtings,
Running up towards my curtains;
This is the one I should keep at bay,
At least that's what the experts say.

To stop it getting on any furniture
And becoming a permanent feature.

I whizz around and polish each room
And hoover up with a HEPA vacuum.

I'm pretty sure that it's not too late
To open my windows and ventilate,
And wash the walls with lots of bleach
Everywhere I can possibly reach.

I will stop the nuisance before it spreads
And tries to rear its beastly head.
As long as I keep up with all my chores,
There won't be problem with those spores.

So there's no reason to live in fear.
Just try to avoid a damp atmosphere.
Not too hot and not too cold
Should keep away that nasty mould.

*Chris Harris,
National Aspergillosis Centre Manager.*

Hospital car park

Here I lie in the rush of life
under engines revving, headlights shining as rain falls
and tyres track through puddles.
Cars are jostling, then parking higgledy-piggledy.
People are coming and going: happy, anxious, sad, relieved.
Some dash, others are sauntering along.
I see pregnant women waddle in
and come out with bundles of joy.

The buzzer's buzzing as the gate opens, closes.
There's shouting, cheering – someone's spotted a space!
There's shouting, swearing – someone's nicked their place!
I hear car doors slam, keys rattling, chatter, chatter,
the chink of coins, drone of planes, wheels slopping water
from my potholes, engines stopping, starting, indicators
ticking as cars are turning, turning.
The noise, *the Noise!*

Phones are ringing, worry, laughter, children crying
who wanted to go before they came.
Now someone's cursing
"Space but no spaces,
lines but no ends,
pay-machine
but no change."

In the dark, I hear wind in the grass
and bits of paper blown round my empty self.
But morning's tyres soon screech and halt

followed by the clip clip clop of people's feet,
stones underfoot. Then I know that moans
are about to start about being charged.

I am very important – people would be angry
if I wasn't here. I'm taken for granted!

But when I feel downtrodden, unloved, forgotten
under the weight of traffic, I remember
when there were fields around here:
bird-song, sheep baa-baaing, herds of cows,
rumbling tractors and horse-drawn carts,
family picnics and the shouts of ball games.
I remember the charity days: people dressing up and stalls.
I remember the nurses' home and sanatorium,
tuberculosis patients getting the air.

Or, when I feel downtrodden, unloved, forgotten,
I can dream of waking on Christmas morning
full of snow – with not a single tyre track.
I can dream of waking re-surfaced with sleek black tarmac
and flashy yellow lines showing patients where to park
– or that Santa has left me covered with sports cars!
Perhaps I could retire somewhere hotter, less wet?
Or move to a residential area and make friends.

But more than anything, I dream
of no pain being given out to anyone.
I dream of every family
who went in worried
returning to their car

with a smile on their face.
I dream of all those moments
when I am a garden
of good news.

Aspergillosis Support Group Poem
written with Caroline Hawkridge, Writer-in-Residence,
National Aspergillosis Centre.

'Hope is...'

Hope is when someone listens to me,
when they hear what I say.
Hope is when tomorrow is another day
and not just yesterday again.

Hope is my wife's good night's sleep
and a smile on her face ... & its magical!!!!
Hope is daffodils and a bright shining light
at the end of a VERY dark tunnel.
Hope is feeling happy or at least normalised
when pain goes intolerable.
Hope is a street between two cathedrals
(especially if you know Liverpool!).
Hope is seeing more people laughing
instead of moaning.
Hope is the spark for this poem.

Hope is the spring that will come soon
and bring along the flowers that bloom.

Hope is that a solution may be found
to release me from the pain,
that there's better times to come.
Hope is having another day to spend
with my children and grandchildren.

Hope is my husband and two daughters.
Hope is friends out there we can turn to
for 'been there done that' advice
& 'this is how I coped with it'.
Hope is successful treatment

and seeing tomorrow's dawn and sunset.
Hope is 'the last infirmity of a noble mind'
(and someone quoting Milton!).

Hope is to do some, to do it yourself,
that tomorrow is as good as today.

Hope is belief, a higher power.
Hope is the name of our doctor's daughter, Aml.
Hope is bright with a smile.

Hope is planning my joint birthday party
with its yellow and orange balloons
and the dolls' tea-party the young children
are going to have there.

Hope is not for today. For today, to get out of bed, is all I can do
and its hours and hours before I can lay down my head.
But hope is for tomorrow, when all will be well
and this is the story I myself will tell.

Hope is like the sea that touches every part
of our planet no matter where patients live.
Together we can build "A SEA OF HOPE"
that anyone & Everyone can either dive
into or just "Dip their own toe".

Hope is breathing for many years to come
– and Easter eggs at our next group meeting!

Aspergillosis Support Group Poem
written with Caroline Hawkridge, Writer-in-Residence,
National Aspergillosis Centre.

**Rachel Collett,
Ellesmere Port Catholic High School**



Artwork shortlisted for the National Aspergillosis Centre's **Project LIFE Schools Competition 2012** supported by the Fungal Research Trust, www.projectlifecompetition.org

Aspergillus in a well-loved pillow

All night
you breathe
my hyphae.

Your white blood cells seek,
then eat me; snip, stop
my stitch-up.

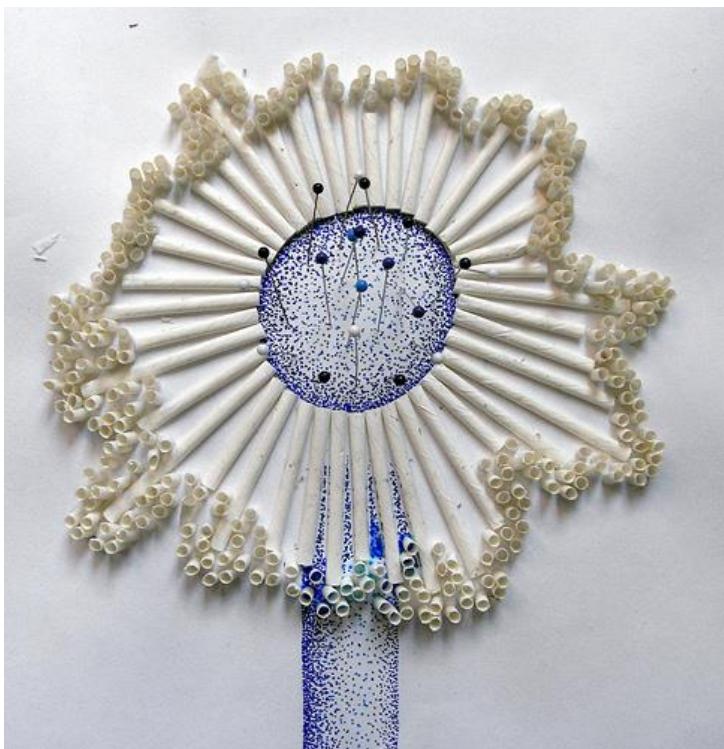
You won't face months
of coughing up buttons, dark
mucous plugs.

No x-rays for balls of my silks.
No drugs trying to heal where I left
all my needles.

*Caroline Hawkridge,
Writer-in-Residence, National Aspergillosis Centre.*

Caroline wrote this poem in response to Rachel Collect's artwork. The poem was first published in special edition on fungi of the international PAN journal (Philosophy Activism Nature).

Sarah Woodward, Stockport College



Artwork shortlisted for the National Aspergillosis Centre's **Project LIFE Schools Competition 2012** supported by the Fungal Research Trust,
www.projectlifecompetition.org

Aspergillus (Micheli, 1729)

Eye at the lens,
the priest saw
an aspergillum:

holy water sprinkler,
God's geometry, a 'flower' ready
to shake out 'seed'.

From Micheli's illustrated catalogue
of moulds, the name spread
to find you here.

*Caroline Hawkridge,
Writer-in-Residence, National Aspergillosis Centre.*

Erica Inglis, Stockport College



Artwork awarded 2nd prize in the National Aspergillosis Centre's **Project LIFE Schools Competition 2012** supported by the **Fungal Research Trust**, www.projectlifecompetition.org

Filamentous fungi

Each nib fine-inks
the unseen

ever-lengthening
corridors of chiton-glucan.

Watch new nibs sharpen,
paths square off and scratch

at tissue: life's colour-wash,
hint of blood and rust, head

in the clouds and every breath's
two bags full.

*Caroline Hawkridge,
Writer-in-Residence, National Aspergillosis Centre.*

Caroline wrote this poem in response to Erica Inglis's artwork.
The poem was first published in special edition on fungi of the
international PAN journal (Philosophy Activism Nature).

National Aspergillosis Centre

The National Aspergillosis Centre (NAC) was founded in 2009 by the National Commissioning Group (NHS), which funds smaller specialist NHS centres (less than 1000 patients) in the UK, to treat Chronic Pulmonary Aspergillosis. It has rapidly become the foremost centre for the treatment and research of this illness and others involving the fungus Aspergillus such as Allergic Bronchopulmonary Aspergillosis (ABPA). Working closely with the North West Lung Centre at UHSM, Manchester, the NAC also treats other infections involving the fungus Aspergillus including severe asthma (SAFS).

*The National Aspergillosis Centre is
the only specialist medical centre
focused on Aspergillosis in the
world*

Aspergillus & Aspergillosis

Aspergillus is a fungus that is present in the air that we breathe almost anywhere in the world. It spreads by producing minute spherical spores (50 times smaller than the diameter of a human hair) that are small enough to penetrate deep into our lungs.

For the most part our lungs destroy these spores immediately but in some people the spores can persist and grow causing a serious infection (Aspergillosis) that can make breathing difficult.

Why this is important

- Aspergillosis is a severe debilitating infection that affects the health of many millions of people throughout the world
- There is no cure for Aspergillosis; diagnosis is difficult
- Aspergillus infection has many more victims, including those with severe asthma
- 1 in 350 could be affected



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