

# News *etter*

## A need, a vision

First impressions can transform lives. An experience I vividly recall as a medical student concerned a middle aged lady whose life was devastated by the onset of urinary incontinence. I was intrigued and impatient to learn how she could be helped. At her case discussion, the consultant focused exclusively on her rare diagnosis, a subject about which he had encyclopaedic knowledge. The management of her incontinence was summarily dismissed. Later enquiries revealed the patient was advised to purchase a large bath towel, to cut it into small squares and put them inside her pants. Problem solved!

Over the years, it became obvious this was not an isolated experience. A steady stream of patients was being referred to the hospital every

week with catheter problems, to be seen by nurses or junior medical staff. A study we conducted in the 1990's revealed that 72% of patients with long term catheters experienced some complication, with blockage and leakage around the catheter being the most common.

The concept of the BioMed Centre arose from a series of brain-storming sessions, to initiate multi-disciplinary research, and to build dedicated clinical and laboratory facilities to investigate and design novel user-friendly and effective urine collection systems. The BioMed Healthcare Technology Cooperative introduces a new and promising chapter in that evolution.

**Professor Roger Feneley,**  
Chairman of the BioMed HTC



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## Contents

A need, a vision

*Professor Roger Feneley*

### Feature

Focus on Users

Fred's story

Sidney's story

My Last Walk

*James Gregory*

### Innovation

User-designed device – the ALBERT

*Trevor Wills*

PromoCon: bringing users views to  
continence product development

*Debra Evans*

BioMed HTC gets INVOLVED

BioMed Director of Research wins  
Innovation Award

### Research

Preventing encrustation by drinking  
lemon juice

*Azhar Khan*

Catheter blockage or no catheter  
blockage? That is the question...

*Nicola Morris*

Incontinence and older people: is there a  
link to social isolation?

*Angela Hogg*

What exactly do patients need to manage  
their continence?

*Sarah Fowler*

### Education and Practice

The Biomed Catheter Clinic

Workshop for the RCN Continence Forum

### News, Events and Fundraising

More 'Friends' for BioMed

Generous donations for BioMed Centre

Jan runs the half-marathon

Fundraising: Why and How?

# Focus on Users

Two of Professor Feneley's patients tell their story. We are grateful to Fred and Sidney for permission to publish their accounts.

## Fred's story

My name is Fred and I have MS. When my bladder control became difficult I was advised to have a suprapubic catheter inserted. It was fantastic. It gave me much more freedom and the only inconvenience was having the catheter changed every 12 weeks. So it was a real shock when one day, out of the blue, my catheter blocked. Not knowing what to do my wife Peggy called the District Nurse who came to our house and changed the catheter. All was well for a day or so, but then it blocked again. And again. And again. The next few weeks were a nightmare as we had to call for emergency help at all hours of the day and night. Changing the type of catheter didn't help, bladder wash-outs made little difference and I was not offered any other alternatives.

With the prospect of a long wait for an NHS appointment and in desperation to find a solution, I decided to see a consultant urologist privately. Within a few days I had an appointment. The consultant took an X-ray and urine sample. A few days later, while waiting for the test results, my wife happened to see an article written by Professor Feneley. She decided to write to him for advice, adding her phone number as an after thought. To our great surprise, Professor Feneley 'phoned and invited us to attend the

BioMed Catheter clinic the following day. There I had a cystoscopy examination and the probable cause of the blockage was discovered - a large bladder stone. The doctor said he would try to remove it but that it may cause some pain. I told him I would just scream. "Too late!" he said, holding up the stone. That same day, I received a letter from the consultant I had seen privately advising me to have the stone removed under general anaesthetic. As far as we are concerned going to the BioMed clinic was the best thing that happened to us!

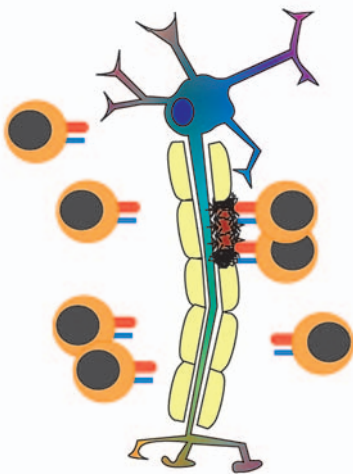
For more information on the BioMed Catheter clinic, contact Deborah Rigby on 0117 959 5188.

## Sidney's story

My name is Sidney. I was born on 19th February 1938 with spina bifida. My mother was told 'take him home and he'll be dead in three months'. My place of birth was Greenwich, London. Soon after I was born my parents moved to a rented bungalow in Dagenham, Essex. When I was about 4 years old I was evacuated until the end of the war in 1945.

In the period prior to the NHS in 1948, my parents used to take me to Aldchurch Hospital just to see a doctor (no treatment), at a cost of 1shilling and 6 pence. On one occasion I was admitted to the hospital for a few days for observation. While I was there my parents and two brothers were evicted from their home and ended up staying with an aunt and uncle in a two bedroom flat in South London. Within two weeks of my leaving hospital my family ended up in the work-house.

After a few weeks I was put into a Children's home (for delinquent boys) as there were no provisions for children with a disability, or as we were labelled in those days, 'cripples'. I experienced a year of what today would be called 'child abuse', by being caned every day I had a wet bed, because I was said to be lazy.



T cells attacking a nerve cell sheath in the brain of a patient with multiple sclerosis

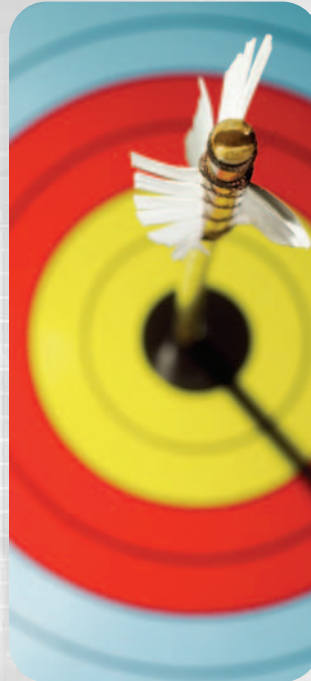
Image used with kind permission of Dr Lindsay Nicholson

In 1949 I eventually went into a children's home in Wellingborough. I was there until I was 16 years old. It was here that I started my education properly. During this time lads with spina bifida had to wear nappies (how degrading). In December 1953 I went into Kettering General Hospital, where I had my right leg amputated below the knee, a right groin operation and an operation on my left foot, all on the same day.

After leaving school, Easter 1954, I went to Roehampton Limb-fitting Centre. It was decided to operate on my deformed hip and I ended up in a plaster jacket for 9 weeks of a 5 month stay in hospital. After leaving hospital I managed to get a job repairing deaf aids. I had to leave when my family moved to Kent. I was out of work for over a year while my application for transport (invalid trike) was being processed. I eventually got a job with a firm called Londex, making Electronic Switch Gear. This was 1956, during which time I went into Roehampton hospital to have a re-amputation through the knee. Whilst at Londex I did an Electronics Course at Lewisham Technical College.

Then in 1966 I went to work for Post Office Telephones (now BT). I worked for this organisation until I took early retirement in 1989. In March 1968, BT sent me on a 3 week STD course. At the end of the first week, I met Mary, who was to become my wife. We got engaged in the August, I requested a transfer with BT and moved to Bristol in April 1969. Mary's sister Ann, (a nurse), put me up until Mary and I got married on 9th August 1969. From the day I met Mary, it was the first time in my life that my waterworks problems were accepted for what they were, a part of my disability.

Our first home was two rooms on the Gloucester Road, this was after many rejections due to prejudice over our disabilities. We stayed at our first address until March 1970, when the Council offered us a flat. A few weeks later Mary discovered she was pregnant, and on December 11th 1970, our son Adrian was born by caesarean section. We did



however, find some prejudice, one person in the flats told the caretaker's wife that 'people like us should not be allowed to have children'. Whereas the visiting sister said that if all babies were as well looked after as Adrian she wouldn't have any work to do.

From the time that I left school I used to wear a bag as my bladder was not emptying properly, and I was regularly getting infections. It was suggested that to help empty my bladder I should apply pressure, this did help to an extent and the water infections did reduce a little. When Mr Feneley suggested I should self catheterise it gave me a new lease of life. The infections were down to a minimum and I was able to enjoy activities without having embarrassing moments. I do still have some extra protection, by using pads. One of the activities Mary and I enjoy, is indoor bowls and we can be on the green for up to four hours at a stretch. Only once in over twenty years have I ever come off the green during a match to go to visit the toilet. Previous to bowling, I have taken part in archery and winter sports (cross country and ice hockey).

In conclusion, the things that have changed my life for the better are: The NHS, Mr Feneley, the catheter and last, but not least, my wife Mary and my wonderful family. I am a proud father, and grandfather to three super grandchildren. When I left school I would never have believed I would have such a wonderful life.



# My Last Walk, Pictures and Poetry by Paralysed People

If you had to capture and explain the intensity and enormity of human emotion when faced with the mountain of an acute spinal injury, individuals would give differing views.

Coincidences happen and, for whatever reason, people find themselves thrust together in a totally alien environment to that which they are used to. What unravels along the unintended and unwanted journey are a few gems, thoughts plucked at opportune moments under the guidance of an expert in the creative and healing arts.

So begins the journey from the point of accident through rehabilitation and looking to the future and discharge back into the world that will hopefully be conveyed in this small collection.

Often people ask "how do you cope?", "why me?", "I'm not sure I could do it". Beyond the obvious lies the inner dialogue and the wrestle to find a new identity.

To reach these places from an outsiders' viewpoint requires focus and concentration, disciplines not always applauded in our instant culture. At the same time try to put yourself in their position and ask yourself what would you do. Within these individuals required the search and vision of looking up, forward out to a place beyond the boundaries that were placed upon us at the time.

The opportunity to be different, to take a chance, go out on a limb, experience the unknown and find the rush and

buzz that is so chained and constrained by the limits of paralysis and spinal injury. To break free from the kit and equipment, ignore the clock and the staff changing and all the other demands of life. That dreaded word "multidisciplinary"; is that not like trying to throw a paper dart into a hurricane? "The system" – who does it work for?

And, as time progresses, brief glimpses of normality and personal identity emerge. The simple and finer things of life, small details that help create the larger picture. The pieces are put back together and slowly one feels whole again.

**James Gregory**

## Poems from My Last Walk,

*reproduced with the kind permission of the authors*

### This Morning

A hand stroked my arm twice.  
I opened my eyes in the gloom  
to see a pretty face and hear  
a whispered voice: 'Annie,  
time to turn you Annie'.

Rice Krispies for breakfast  
But Phil has toast.  
I stroke my legs  
– but they are numb  
still, and they always will be.

I had dreamed that  
loose-limbed and free  
I rode my horse and flew.

**Annie Maw**

### The Door

Big heavy steel door  
with bolts, green peeling paint  
rusty round the edges  
big rivets

can't open it  
amazing places  
on the other side  
no access  
none

Can't open it.  
And if it was open  
I couldn't go through.

**James Gregory**



The BioMed HTC has made a DVD about living with a urinary catheter. Fred, Sid and Annie feature in the DVD. If you would like a copy to use to help raise funds for the BioMed Centre please contact Janice on 0117 959 5690.

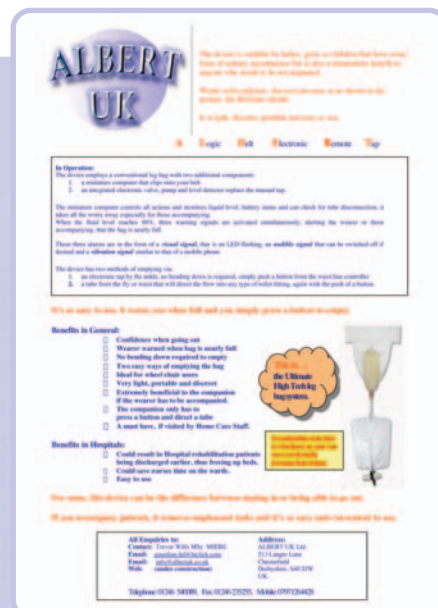
**The book My Last Walk can be obtained from, [jrcgregory74@yahoo.co.uk](mailto:jrcgregory74@yahoo.co.uk) at a cost of £5.00. All profits go to Back Up Trust, John Grooms and Spinal Patient's Art Group.**

## User-designed device - the ALBERT by Trevor Willis

ALBERT - A Logic Belt, Electronic Remote Tap - is my fathers name. The device was developed because of a real need following my father's severe stroke. The original device was designed with stroke patients in mind, but it soon became apparent that the need extended to other catheter users. This has resulted in a number of different models being produced. The unit is a computerised leg bag system that is simple to operate, the user being automatically warned when the bag is nearly full. It is easy to empty

simply by directing a tube and pressing a button, making the process much more acceptable than with conventional leg bags. The features have the added benefit of reducing a patient's anxieties around fluid intake, which should lead to reduced levels of urinary tract infection.

**For further information please contact: Email: [guardian.ltd@btclick.com](mailto:guardian.ltd@btclick.com) or [info@albertuk.co.uk](mailto:info@albertuk.co.uk)**



The device is suitable for babies, grown up children that have not been of suitable age for surgery and it also has a convenient design to ensure the user is comfortable.

It is a fully computerised electronic unit.

English, Irish, Spanish, Korean, Thai

**ALBERT UK**

**Operation:**

1. A computerised electronic unit is connected to the leg bag.
2. An integrated electronic remote pump and level detector replace the manual bag.

The automatic computer controls all actions and monitors fluid level, battery status and can check for water distribution. It alerts the user when necessary for these operations. When the fluid level reaches 90%, three warning signs are activated simultaneously, during the water in these circumstances the leg bag is nearly full.

Three flow status are on the front of a visual signal, this is an LED lighting, an audible signal that can be switched off and a vibration signal similar to that of a mobile phone.

The device has two methods of emptying via:

1. an electronic tap in the tube, on holding down a required, remote pump a button from the rear the container.
2. a cable from the PC or water that will draw the flow into any type of holding, again with the push of a button.

It's an easy to use, it makes your urine full and you don't have to get up to empty!

**Benefits to General:**

- Confidence when going out.
- Wearer warned when bag is nearly full.
- The handling device required to empty.
- Easy care ways of emptying the bag.
- Ideal for short/short stays.
- Very light, portable and discreet.
- It is easily handled by the caregiver if the wearer has to be accompanied.
- The computerised unit has a power button and direct a cable.
- A neat hose, if visited by Home Care Staff.

**Benefits to Hospital:**

- Could result in hospital rehabilitation patients being discharged earlier, thus freeing up beds.
- Could save money time on the wards.
- Easy to use.

**Other notes:** This device can be used for the difference between existing leg bag to leg bag for use.

**UK sales enquiries, patients, if you have any questions, call 0161 834 2001 or email [info@albertuk.co.uk](mailto:info@albertuk.co.uk)**

<p><b>All Enquiries to:</b></p> <p>Company: Guardian Ltd, Unit 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64, 65, 66, 67, 68, 69, 70, 71, 72, 73, 74, 75, 76, 77, 78, 79, 80, 81, 82, 83, 84, 85, 86, 87, 88, 89, 90, 91, 92, 93, 94, 95, 96, 97, 98, 99, 100, 101, 102, 103, 104, 105, 106, 107, 108, 109, 110, 111, 112, 113, 114, 115, 116, 117, 118, 119, 120, 121, 122, 123, 124, 125, 126, 127, 128, 129, 130, 131, 132, 133, 134, 135, 136, 137, 138, 139, 140, 141, 142, 143, 144, 145, 146, 147, 148, 149, 150, 151, 152, 153, 154, 155, 156, 157, 158, 159, 160, 161, 162, 163, 164, 165, 166, 167, 168, 169, 170, 171, 172, 173, 174, 175, 176, 177, 178, 179, 180, 181, 182, 183, 184, 185, 186, 187, 188, 189, 190, 191, 192, 193, 194, 195, 196, 197, 198, 199, 200, 201, 202, 203, 204, 205, 206, 207, 208, 209, 210, 211, 212, 213, 214, 215, 216, 217, 218, 219, 220, 221, 222, 223, 224, 225, 226, 227, 228, 229, 230, 231, 232, 233, 234, 235, 236, 237, 238, 239, 240, 241, 242, 243, 244, 245, 246, 247, 248, 249, 250, 251, 252, 253, 254, 255, 256, 257, 258, 259, 260, 261, 262, 263, 264, 265, 266, 267, 268, 269, 270, 271, 272, 273, 274, 275, 276, 277, 278, 279, 280, 281, 282, 283, 284, 285, 286, 287, 288, 289, 290, 291, 292, 293, 294, 295, 296, 297, 298, 299, 300, 301, 302, 303, 304, 305, 306, 307, 308, 309, 310, 311, 312, 313, 314, 315, 316, 317, 318, 319, 320, 321, 322, 323, 324, 325, 326, 327, 328, 329, 330, 331, 332, 333, 334, 335, 336, 337, 338, 339, 340, 341, 342, 343, 344, 345, 346, 347, 348, 349, 350, 351, 352, 353, 354, 355, 356, 357, 358, 359, 360, 361, 362, 363, 364, 365, 366, 367, 368, 369, 370, 371, 372, 373, 374, 375, 376, 377, 378, 379, 380, 381, 382, 383, 384, 385, 386, 387, 388, 389, 390, 391, 392, 393, 394, 395, 396, 397, 398, 399, 400, 401, 402, 403, 404, 405, 406, 407, 408, 409, 410, 411, 412, 413, 414, 415, 416, 417, 418, 419, 420, 421, 422, 423, 424, 425, 426, 427, 428, 429, 430, 431, 432, 433, 434, 435, 436, 437, 438, 439, 440, 441, 442, 443, 444, 445, 446, 447, 448, 449, 450, 451, 452, 453, 454, 455, 456, 457, 458, 459, 460, 461, 462, 463, 464, 465, 466, 467, 468, 469, 470, 471, 472, 473, 474, 475, 476, 477, 478, 479, 480, 481, 482, 483, 484, 485, 486, 487, 488, 489, 490, 491, 492, 493, 494, 495, 496, 497, 498, 499, 500, 501, 502, 503, 504, 505, 506, 507, 508, 509, 510, 511, 512, 513, 514, 515, 516, 517, 518, 519, 520, 521, 522, 523, 524, 525, 526, 527, 528, 529, 530, 531, 532, 533, 534, 535, 536, 537, 538, 539, 540, 541, 542, 543, 544, 545, 546, 547, 548, 549, 550, 551, 552, 553, 554, 555, 556, 557, 558, 559, 560, 561, 562, 563, 564, 565, 566, 567, 568, 569, 570, 571, 572, 573, 574, 575, 576, 577, 578, 579, 580, 581, 582, 583, 584, 585, 586, 587, 588, 589, 590, 591, 592, 593, 594, 595, 596, 597, 598, 599, 600, 601, 602, 603, 604, 605, 606, 607, 608, 609, 610, 611, 612, 613, 614, 615, 616, 617, 618, 619, 620, 621, 622, 623, 624, 625, 626, 627, 628, 629, 630, 631, 632, 633, 634, 635, 636, 637, 638, 639, 640, 641, 642, 643, 644, 645, 646, 647, 648, 649, 650, 651, 652, 653, 654, 655, 656, 657, 658, 659, 660, 661, 662, 663, 664, 665, 666, 667, 668, 669, 670, 671, 672, 673, 674, 675, 676, 677, 678, 679, 680, 681, 682, 683, 684, 685, 686, 687, 688, 689, 690, 691, 692, 693, 694, 695, 696, 697, 698, 699, 700, 701, 702, 703, 704, 705, 706, 707, 708, 709, 710, 711, 712, 713, 714, 715, 716, 717, 718, 719, 720, 721, 722, 723, 724, 725, 726, 727, 728, 729, 730, 731, 732, 733, 734, 735, 736, 737, 738, 739, 740, 741, 742, 743, 744, 745, 746, 747, 748, 749, 750, 751, 752, 753, 754, 755, 756, 757, 758, 759, 760, 761, 762, 763, 764, 765, 766, 767, 768, 769, 770, 771, 772, 773, 774, 775, 776, 777, 778, 779, 780, 781, 782, 783, 784, 785, 786, 787, 788, 789, 790, 791, 792, 793, 794, 795, 796, 797, 798, 799, 800, 801, 802, 803, 804, 805, 806, 807, 808, 809, 810, 811, 812, 813, 814, 815, 816, 817, 818, 819, 820, 821, 822, 823, 824, 825, 826, 827, 828, 829, 830, 831, 832, 833, 834, 835, 836, 837, 838, 839, 840, 841, 842, 843, 844, 845, 846, 847, 848, 849, 850, 851, 852, 853, 854, 855, 856, 857, 858, 859, 860, 861, 862, 863, 864, 865, 866, 867, 868, 869, 870, 871, 872, 873, 874, 875, 876, 877, 878, 879, 880, 881, 882, 883, 884, 885, 886, 887, 888, 889, 890, 891, 892, 893, 894, 895, 896, 897, 898, 899, 900, 901, 902, 903, 904, 905, 906, 907, 908, 909, 910, 911, 912, 913, 914, 915, 916, 917, 918, 919, 920, 921, 922, 923, 924, 925, 926, 927, 928, 929, 930, 931, 932, 933, 934, 935, 936, 937, 938, 939, 940, 941, 942, 943, 944, 945, 946, 947, 948, 949, 950, 951, 952, 953, 954, 955, 956, 957, 958, 959, 960, 961, 962, 963, 964, 965, 966, 967, 968, 969, 970, 971, 972, 973, 974, 975, 976, 977, 978, 979, 980, 981, 982, 983, 984, 985, 986, 987, 988, 989, 990, 991, 992, 993, 994, 995, 996, 997, 998, 999, 1000.</p>	<p><b>Address:</b></p> <p>ALBERT UK Ltd</p> <p>10, 11, 12, 13, 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## PromoCon: bringing users views to continence product development

PromoCon (PROMoting CONTinence and product awareness) helps people with bladder and bowel problems their carers and health and social care staff. It is part of the charity Disabled Living, based in Manchester. It provides a national service to help people to make informed choices about which continence products are most suitable for their needs. This is done by raising awareness and by providing impartial advice and information on products equipment and services available in the UK to improve quality of life.

PromoCon works in partnership with over 250 companies. The knowledge and expertise of the PromoCon team combined with information we receive from members of the public and healthcare professionals puts us in a unique position to identify the gaps in product availability and provision.

Please contact PromoCon for advice and information relating to continence products and services: Tel: **0161 834 2001** – Confidential Helpline (Monday –Friday 10am – 3pm). Email: [debra.evans@disabledliving.co.uk](mailto:debra.evans@disabledliving.co.uk) Web: [www.promocon.co.uk](http://www.promocon.co.uk)

## BioMed HTC gets INVOLVED

User feedback is essential for successful device design and the BioMed HTC philosophy is to involve patients and carers at all stages. All too often, healthcare professionals and product designers focus on finding a solution to a 'clinical' problem without consulting product users as to the design features that would enhance their quality of life. How users can be more involved, at what stage and who should pay are tricky issues. To pick up some tips, Debra Evans and Adele Long presented the work of the BioMed HTC at the Department of Health's INVOLVE

conference in September 2006. What they discovered was that users themselves were the best at giving the message to other users. As to who pays and what amount, the jury seems to be out!

If you wish to be involved in the work of the BioMed or you have any thoughts on how patients and carers could or should be involved, please contact us at the **BioMed Centre** or complete the membership form (contact **Janice** on **0117 959 5690** or alternatively download it from the website

## BioMed Director of Research wins Innovation Award

Earlier this year Dr David Stickler was awarded the Medical Engineering Division of the Institute of Mechanical Engineers' Innovations Prize 2005 for his paper "Development of a Sensor to Detect the Early Stages of Catheter Encrustation" Plans to bring the sensor to market are underway.



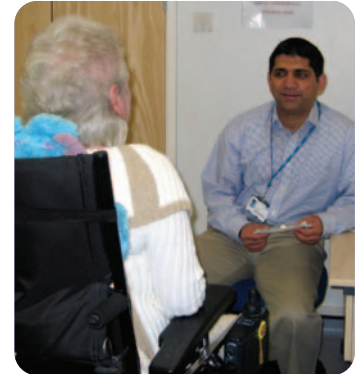
[www.biomedhtc.org.uk/Membership](http://www.biomedhtc.org.uk/Membership) In addition you can join the UK Clinical Research Collaboration by contacting [Philippa.yeeles@ukcrc.org](mailto:Philippa.yeeles@ukcrc.org) or telephoning **020 7670 5153**.

### Preventing encrustation by drinking lemon juice

About half the people with long-term indwelling catheters suffer from the complication of catheter blockage. This is caused by a bacterium *Proteus mirabilis* and results in a build-up of crystals inside the catheter, known as encrustation. We have found in laboratory experiments that if we raise the nucleation pH of the urine we are able to reduce the rate of encrustation, and that by increasing the concentration of citrate in the urine, we can raise the nucleation pH. Citrate can easily be taken

as potassium citrate, which is available over the counter as a standard treatment to reduce the burning sensation felt with cystitis, or in drinks made with lemon or lime juice. We are now investigating whether our results in the laboratory can be replicated in people. If so, the use of citrated drinks may provide a simple, inexpensive and effective strategy for reducing the rate of catheter encrustation.

**Dr Azhar Khan**, Research Fellow



### Catheter blockage or no catheter blockage? That is the question...

Previous work has shown that there is a small group of patients that, although infected with *Proteus mirabilis*, do not suffer the complications of catheter encrustation and blockage. We don't know if this phenomenon is due to the effects of other bacteria present on the catheter, an individual's genetic characteristics or lifestyle factors. This study, funded by the Frances

and Augustus Newman Trust, is investigating the first of these possibilities. Knowing why something doesn't happen can be as revealing as knowing why it does, and could lead to the development of novel strategies for the control of catheter encrustation and blockage.

**Dr Nicola Morris**, Research Manager

If you have any comments or are interested in taking part in these studies, please contact Azhar or Nicola on **0117 959 5540**

### Incontinence and older people: is there a link to social isolation?

We know loss of bladder control can be distressing. Even the fear of losing control in a public place can cause concern. Funded by Help the Aged, this project seeks to explore whether or not older people feel socially isolated by their incontinence and what environmental and other factors have

most impact. Help the Aged hopes to use the findings to understand if and how government policy, services and provisions are meeting the needs of older people. Dr Helen Godfrey from the University of West of England, Bristol is leading this project.

**Mrs Angela Hogg**, Research Associate



### Understanding the needs, quality of life and cost of long term catheterisation



This study, which started in October 2006, is designed to find out from patients and carers what life is like with a long term indwelling catheter. The results of the study will be used to inform device design and health care service provision and to develop specific tools for measuring quality of life and cost of catheter care. The first phase of the project, funded by the Wright Bequest, will involve interviewing patients who have long

term catheters and developing a questionnaire. The project has follow-on funding through Action Medical Research to fully validate the questionnaire, and will be conducted in collaboration with Professor Kathy Getliffe (Project Lead), Professor Derick Wade, Dr Heather Gage, Dr Mandy Fader and Nikki Gardener, as well as the BioMed team.

**Mrs Sarah Fowler**, Research Associate

If you have any comments or are interested in taking part either of these studies, please contact Angela or Sarah on **0117 959 2440**

## Nursing Lead for BioMed Centre

In July 2006, Deborah Rigby joined the BioMed Centre as Nursing Lead, with a remit to develop the clinical research and educational services. Deborah has been a continence nurse specialist for 17 years and has considerable knowledge of the clinical and social issues around the management of intractable urinary incontinence. In 2003 Deborah won the Nurse of the Year award for her work with urinary incontinence. Her first book 'A

Clinical Handbook for Continence Care' is due to be released this autumn. Deborah's plans for the BioMed Centre include the expansion of the clinical facility to include an assessment room that can be used by community health professionals and which will offer additional space for running trials. She is also developing an educational programme for health care professionals, and establishing a user support group.



## Workshop for the RCN Continence Forum

Diane McNicoll, Continence Advisor for Trafford PCT and facilitator for the RCN Continence Forum in the North West approached the BioMed Centre to ask if we would deliver a workshop for 30 continence advisors and nurses on 'the latest' research evidence particularly in the area of catheter encrustation and its management. Most of all, she said they wanted a provocative debate.

The day started with objective setting by the delegates. These included: how to deal with catheter blockages and expulsion; education, communication and compliance for health professionals as well as patients and carers; and the effect of a cost driven NHS

system on access to products and delivery of care.

All topics were affected in some way by the lack of evidence, hindering development of best practice and thus adversely affecting quality of care. Barriers were identified, solutions suggested and these prioritised by assessing relative impact and difficulty of implementation. The process offered a starting point for personal and group action to change catheter care and understand what may be needed to implement the change.

The second part of the day was spent on the biochemistry and microbiology of encrustation and how *Proteus mirabilis* infection can be tackled. Infection is the big bugbear for catheter users

and there is much publicity around how to prevent or reduce it. Unfortunately a lot of research is difficult to evaluate and compare, since different outcome measures are used. David and Sunil successfully dispelled some of the myths around infection and catheter encrustation, the risks and the treatment.

For the BioMed team it was an excellent opportunity to learn about problems at the coal face and to see how, in partnership, we can move the agenda forward. Delegates summed up the day as "enjoyable" and "informative" and one that "exceeded expectations".

BioMed HTC team: **Ms Adele Long, Dr David Stickler** and **Mr Sunil Mathur**

## More 'Friends' for BioMed

Fundraising can be rewarding, it can be fun, but it can also be time consuming. Taking the view that a problem shared is a problem halved, a small group of about 20 Friends held a second 'tea party' in July in the BioMed Centre to discuss ways of, in the words of Chairman Tim Pearce, 'spreading the gospel'. Then in October, Tim and Judy Pearce kindly hosted a dinner event for 60 invited guests who were introduced

to the work of the BioMed Centre and watched the BioMed DVD. Over £3,800 was raised through donations and a raffle. Even more encouraging was the promise of volunteer help and further fundraising ideas.  
*Thank you Friends.*

We are delighted that our BioMed Friends Chairman was appointed Master of the Bristol Merchant Venturers on Friday 10th November.  
*Congratulations Tim.*



## Jan runs the half-marathon

Janice Hillier, BioMed Administrator ran in the Bristol half marathon in aid of the BUI, raising £533 of which £275 will go towards the BioMed Centre. This was her first half marathon and she ran in under 2 hours 30 minutes. *Well done Jan!*



## Generous donations for BioMed Centre

We have been very fortunate to have received a number of generous donations of money and equipment to provide much needed computing and recording equipment for research staff and a water dispenser for the BioMed Clinic patient's waiting room. Our sincere thanks to: Mr Michael Bothamley, Beachcroft LLP, solicitors to the North Bristol NHS Trust, Nestle Water and to a number of BioMed Friends who wish to remain anonymous. A special thanks goes to John Hughes Associates who have kindly sponsored the printing of this Newsletter.

## Fundraising: Why and How?

The BioMed Centre is part of the Bristol Urological Institute, a charity based in the south west of England. We rely on charitable donations to provide many of our infrastructure and dissemination costs. Every donation helps to support our research and innovation work.

You can donate by completing the form below (or from the web site) and posting it with your cheque to: The BioMed Centre, Bristol Urological Institute,

Southmead Hospital, Bristol BS10 5NB, or electronically through Just Giving by going to [www.justgiving.com/biomed](http://www.justgiving.com/biomed)

Using the Gift Aid scheme enables charities to claim back the income tax on every pound donated by taxpayers. The scheme is administered automatically and does not involve you in any additional paperwork. Please help us further by ticking the Gift Aid box on sponsorship forms.

Mr/Mrs/Miss/Ms/Dr/Other: \_\_\_\_\_ First Name \_\_\_\_\_ Surname: \_\_\_\_\_

Address: \_\_\_\_\_ Post Code: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

I enclose a cheque made payable to BUI BioMed for £ \_\_\_\_\_

Gift Aid Declaration: As a UK taxpayer I want the Bristol Urological Institute to reclaim tax on my donations now and in the future

Name of taxpayer (Print): \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

