

Hydrocephalus Consult & DiaCeph Monitoring Report

w/ recommendations in Integrative Medicine

“A Johns Hopkins Medical Center Patient”

(Permission granted to publish online)

Reason for Consult:

The patient was diagnosed with NPH in February of 2009, and has undergone several surgical procedures to arrest his NPH related complaints. His NPH is complicated by blindness (retinitis pigmentosa) and prostate enlargement. Unsatisfied with his NPH outcome, he contacted me for a patient consult and to undertake non-invasive “DiaCeph” monitoring.

NPH Illness, Surgical History, and Discussion:

My patient was tentatively diagnosed with normal pressure hydrocephalus in Dec. 2008 on an MRI brain scan. He was evaluated clinically by his Internist on 2/25/09, and was admitted to the Johns Hopkins neurology unit on 3/13/09 for a CSF drainage trial where withdrawal of 547 cc of CSF produced a positive response. It was felt, based on that evaluation that the patient’s gait and walking would benefit from CSF diversion surgery, but that his urinary urgency and mild cognitive complaints would likely be unaffected. CT and MRI brain scans demonstrated mild to moderate ventriculomegaly consistent with NPH, and ischemic vessel changes thought related to age. His neurologist felt there was some mild cognitive impairment, more related to dementia than NPH. *An asterisk is added to his CSF drainage results as his report states that the patient’s baseline data was not obtained until after an evening of significant drainage. It is unclear how this might impact the cognitive findings. The patient also has retinitis pigmentosa, which seems to complicate his walking.

On 4/1/09, the patient was admitted to the neurosurgical wing of Johns Hopkins, where a Medtronic Strata valve and Aesculap Shunt Assistant (ASD) 0/20cm H2O were inserted in an occipital site. The Strata was set at 2.5 opening pressure, lowered to 2.0 on 5/1/09, and raised back to 2.5 on 7/16/09. It was lowered back to 2.0 on 7/30/09, and lowered to 1.5

on 9/10/09. During this period, there was no measurable change in ventricular size on CT, and only minimal improvement in walking and gait.

On 10/16/09, the patient was re-admitted for a second CSF drainage trial, which again produced a positive response, and it was suggested he undergo an ETV and shunt revision to lower the physical position of the (ASD) Strata valve, which was accomplished on 11/6/09. The new Strata was set at 1.5. Once at home, the patient began to experience some marked confusion, and over the following weeks, began to suffer headaches, nausea, and dizziness.

On 11/30/09, he was re-admitted to the hospital for evaluation of his dizziness where no evidence of vertigo was found, rather mild orthostatic (postural) changes in blood pressure and slight horizontal nystagmus (eyes). Some tightness and limited mobility was identified in the patient's neck, and physical therapy was suggested to improve his range of motion. According to the records from that admission, the patient commented that the heaviness in his legs was improving, but worse in the evening. He also complained of intermittent episodes of dizziness or "loopyness" throughout the day, and difficulty rising and walking from a seated position. So on 12/17/09 the Strata setting was increased to 2.0, and the next day lowered back to 1.5.

During these revisions and setting changes, it appears there was no change in the size of his ventricles on CT scanning, with a slight improvement in walking, balance, and gait. On 1/4/10, he met with his neurologist who felt he would benefit by a lower setting, and the Strata was lowered to 1.0. The patient shared that he felt overwhelmed by all these medical treatments, and described his NPH and cognitive changes as worrisome. He also has a history of depression.

He returned to his neurologist office on 1/7/10 complaining of feeling loopy and dizzy. His blood pressure was 162/100 and heart rate 105. So the Strata was kept at a setting at 1.0, and the patient was referred for an inner ear workup. It was not long after this, that he contacted me for a consult and DiaCeph monitoring, hoping I could shed light on a treatment plan that might better his outcome with NPH. I do not recall if he obtained an inner ear workup as was proposed.

There has been some difficulty in obtaining accurate outcomes data with this patient's care and treatment, in part because of his blindness, medical staff's difficulty finding the most optimized setting with his Strata valve, and exacerbation of his complaints from antidepressant (amphetamine) medications. During his 2/25/09 workup by his neurosurgeon, he reported that his gait and balance problems had somewhat improved when off the antidepressants.

Other Relevant History:

This patient also has retinitis pigmentosa, diagnosed about 1990, hypertrophy of the prostate, urinary urgency, and is being treated with Flomax. He has been treated for depression for many years, and takes Tenuate Dospan for this. He has non-specific mild cognitive impairment, which could be due to early dementia, and there are vascular and ischemic changes present on his brain scans. He shares that both of his shoulders, and one of his knees, is in need of orthopedic surgery. Clearly, his NPH is the most significant health issue weighing on his mind at this time.

In-Person Work-up and Observations:

This man flew to Newport Beach, California, to see me in March 2010. With a portion of his history provided in advance, I performed an initial 3 hour workup, answered questions, discussed additional monitoring, and advised him of what could be done surgically with and without shunt adjustments. We also discussed his overall health.

I performed a visual assessment of his shunt, but did not pump his valve reservoir. I took a photograph of the right side of his head of the location of his Strata valve. I performed a brief AK (applied kinesiology) finger touch exam of his shunt, using his left arm for the strength/ deficit challenge. As he has problems and weakness in both shoulders, my exam was brief, but did not reveal any pronounced elevation of ICP or deficits around the shunt that might indicate shunt failure or CSF leakage.

I discussed his maintaining an exercise regimen and how it could help his NPH and overall health. I discussed the role of a good diet, particularly, in managing caffeine and sugar intake, and moderating Tenuate so that he could sleep. I discussed the importance of maintaining regular mental, social, and physical activities and its role in his long term neurological health. I described some of the modalities likely available to him under "integrative medicine." During the workup at my home, I brought out some hand drums and percussion instruments and observed him during play, and found him to demonstrate good cognitive focus and musical skill, at or above normal for his age. He showed me his "four-fingered beat" he plays with his hands, and I encouraged him to pursue more of these activities. I suggested that he explore what is available to him when he returns home.

I evaluated his walking and balance skill by observing him walk in his hotel room, and down a hallway unassisted, where he shuffled with feet both wide apart, and close together. I observed him walk down a hallway without shuffling, hesitation, or changes in gait when assisted arm in arm. I observed him to have difficulty with balance and initiation of steps at times and when he got up from a chair. I observed him to be "loopy" after breakfast, and shuffling. We went for a walk and I observed him to have difficulty maintaining his balance, a sway when standing feet together in a corner, and unable to stand heel to toe.

Review of Radiographs on Disks:

I reviewed his CT and MRI brain scans. I am in agreement as seen in the x-rays that he has normal pressure hydrocephalus. I do not see much significant change, if any, in his ventriculomegaly on scan since he was shunted in April 2009. There is a slight change in his 1/7/10 scan. He is to be rescanned again in April 2010, and perhaps this will provide more insight.

I reviewed his last lateral skull x-ray, and the Strata valve assembly can be seen with the distal portion of the valve, which houses the siphon control device, very near the "O" point, the center of the ventricles, perhaps even 1 cm plus below it. I observed the same finding in my personal exam.

Discussion of DiaCeph Monitoring Methodology:

DiaCeph monitoring was undertaken from March 4, 2010 to March 15, 2010. The science behind DiaCeph monitoring in hydrocephalus is that each patient elicits a measurable set of clinical "markers" which reflect shunt or ETV outcome and severity of hydrocephalus. I review the patient's history and complaints, identify the best markers, and create a monitoring schedule. Over a two to three week period, the marker data is collected, and then I tabulate and analyze it for ICP levels, shunt function, and shunt matching. Monitoring is usually done 5-6 times per day for 14 to 21 days in succession. Each monitoring day produces a graph of each of the markers. Monitoring for 14-21 days assures there will be enough data points to produce an accurate distribution of the patient's complaints. In some cases, additional event or activity monitoring is required.

A custom data "form" and user instructions were prepared for this patient. They included:

1. Walking and gait
2. Urinary Urgency
3. Vision
4. Cognitive function
5. Energy
6. Hall Steps count
7. Sleep quality

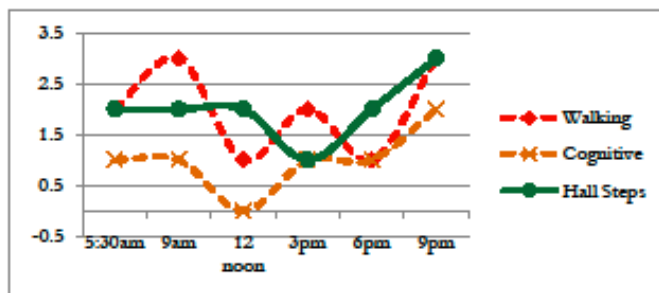
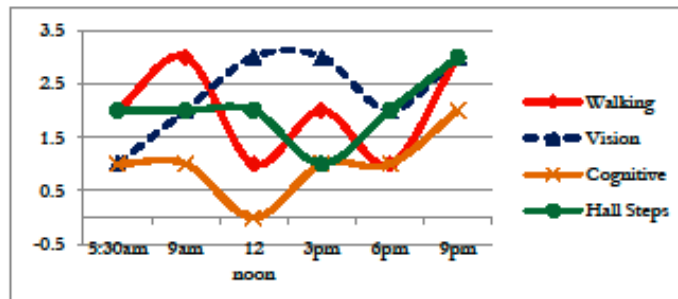
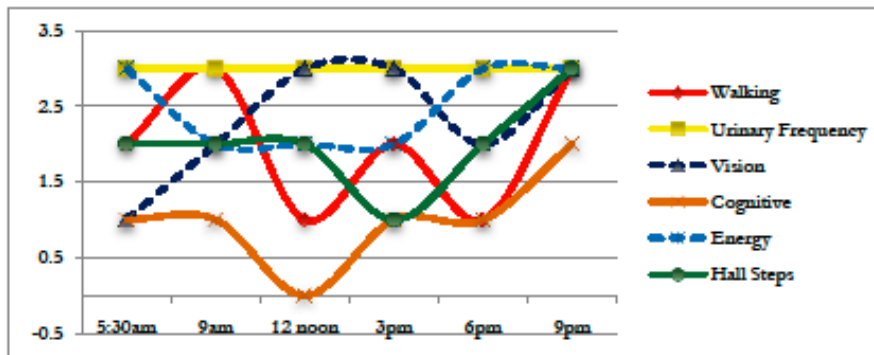
He was instructed to rate 4 of these 7 markers on a scale of normal (N), mild (1), moderate (2), and severe (3). On the Cognitive Test, he used his television to see how many TV programs out of five (5) stations he could remember after a 30 second pause. On the Hall Steps count, he was instructed to count how many steps he could briskly take in his home hallway before taking a mis-step, then to score also between N and 3. On Sleep quality, he was instructed to score as either G (good), F (fair), or P (poor), which I converted to 1-3 scoring.

Mid-way through the monitoring, he developed an acute problem with his left eye, leaving him without any vision in that eye. He has visual impairment from retinitis pigmentosa, and the loss of vision in that eye caused his DiaCeph data from March 9-15th to be incomplete and skewed by this distress. His data from March 4-8th appears in good order. During the 4 days he spent in Newport Beach, I was able to take a history on him, observe his complaints, and gain insight into his health.

Below are DiaCeph/Excel Data Graphs from March 4, 2010 to March 15, 2010, and Comparison Graphs March 4-6

DiaCeph Data Graphs March 4, 2010

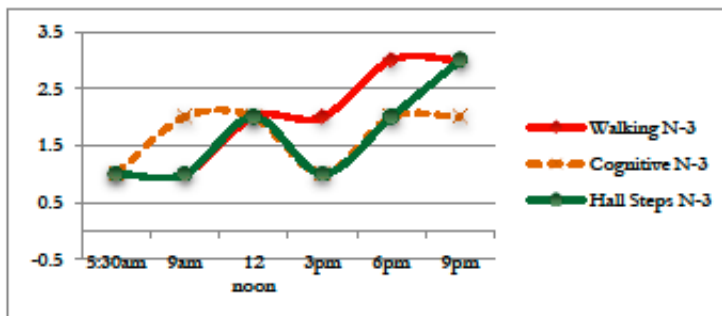
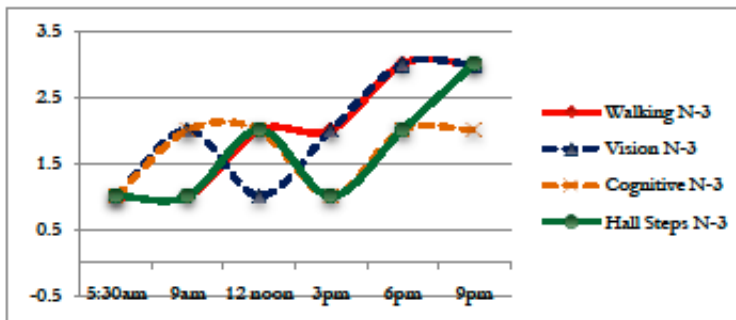
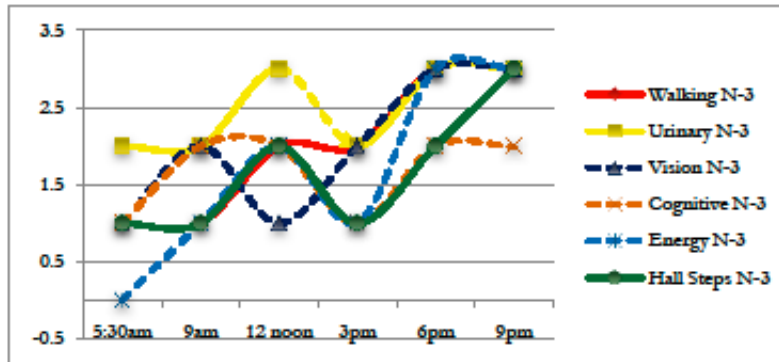
	5:30am	9am	12 noon	3pm	6pm	9pm
Walking	2	3	1	2	1	3
Urinary Fr	3	3	3	3	3	3
Vision	1	2	3	3	2	3
Cognitive	1	1	0	1	1	2
Energy	3	2	2	2	3	3
Hall Steps	2	2	2	1	2	3
Sleep Qual	3	3				
Medication	3	3	3	3	3	3
Headache		2	2			
P/ Physical Activity			2			
P/ Mental Activity			3			



DiaCeph Monitoring by S Dolle On the Web: www.DiaCeph.com

DiaCeph Data Graphs March 5, 2010

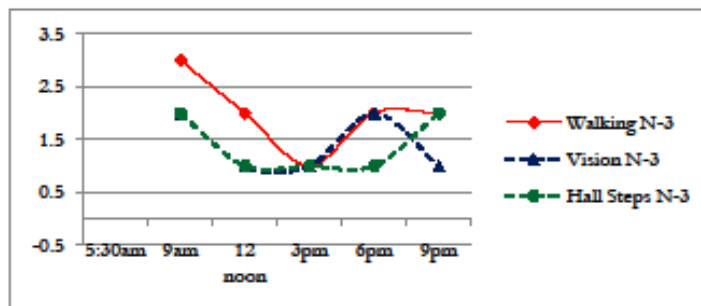
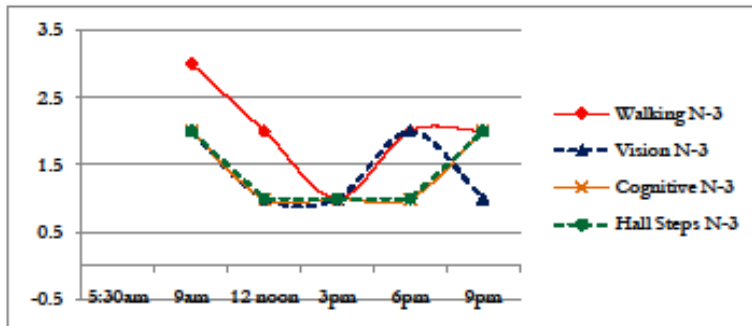
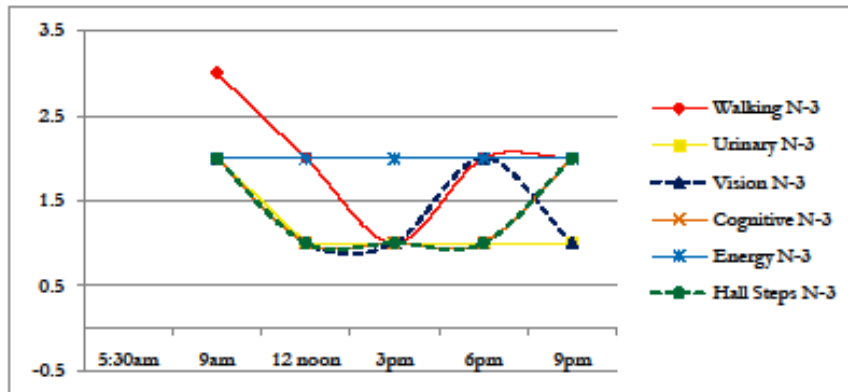
	5:30am	9am	12 noon	3pm	6pm	9pm
Walking N-	1	1	2	2	3	3
Urinary N-	2	2	3	2	3	3
Vision N-3	1	2	1	2	3	3
Cognitive 1	1	2	2	1	2	2
Energy N-	0	1	2	1	3	3
Hall Steps	1	1	2	1	2	3
Sleep Q 1-	2					
Meds 1-3	3	3	3	3	3	3
Headache N-3		2	2			
P/ Physical Activity 1-3			2			
P/ Mental Activity 1-3			3			



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DiaCeph Data Graphs March 6, 2010

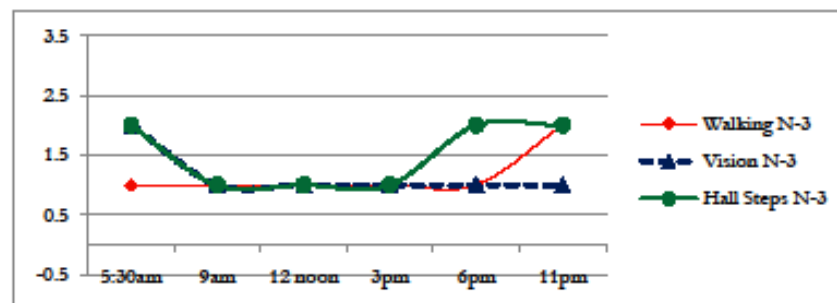
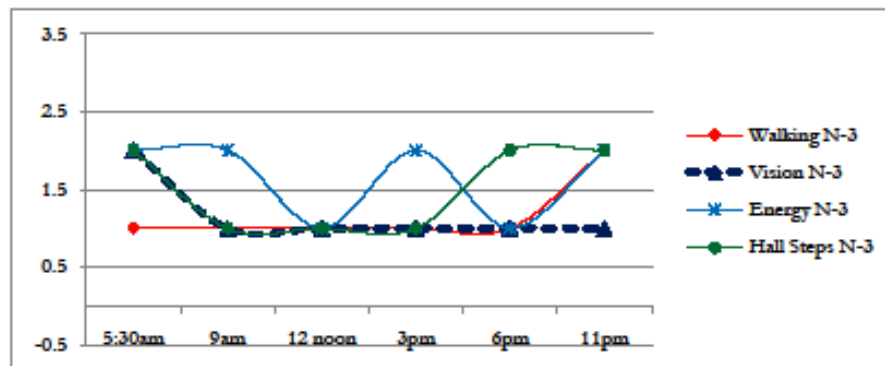
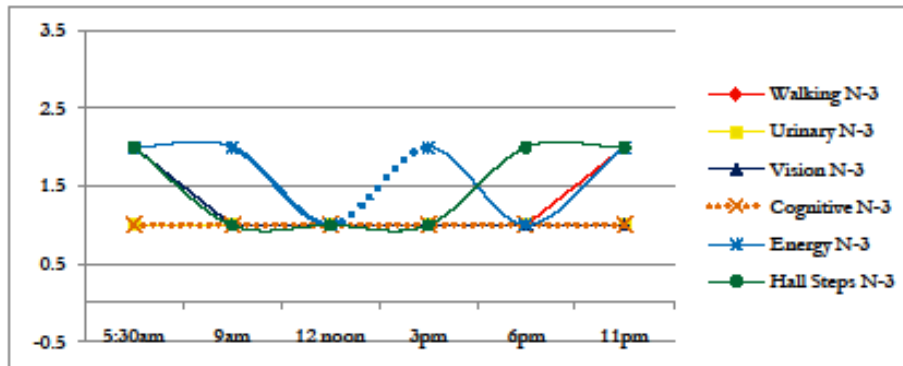
	5:30am	9am	12 noon	3pm	6pm	9pm
Walking N-3			3	2	1	2
Urinary N-3			2	1	1	1
Vision N-3			2	1	1	2
Cognitive N-3			2	1	1	2
Energy N-3			2	2	2	2
Hall Steps N-3			2	1	1	1
Sleep Q 1-3			2			
Meds 1-3	3	3	3	3	3	3
Headache N-3						
P/ Physical Activity 1-3				2		
P/ Mental Activity 1-3				1		



DiaCeph Monitoring by S Dolle On the Web: www.DiaCeph.com

DiaCeph Data Graphs March 7, 2010

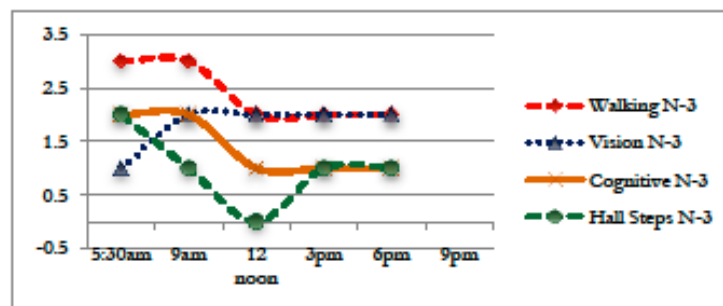
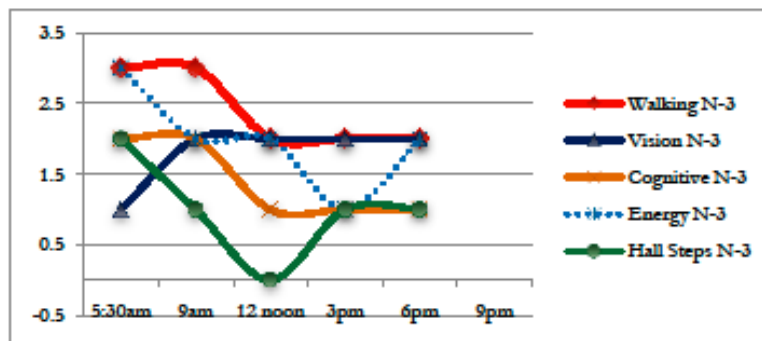
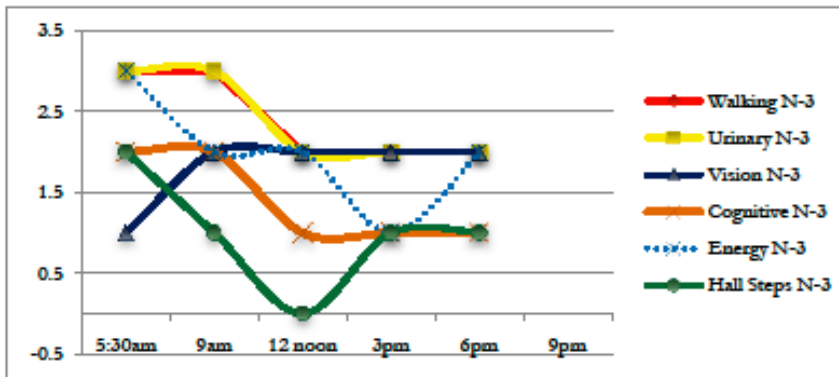
	5:30am	9am	12 noon	3pm	6pm	11pm
Walking N	1	1	1	1	1	2
Urinary N	1	1	1	1	1	1
Vision N-3	2	1	1	1	1	1
Cognitive 1	1	1	1	1	1	1
Energy N-	2	2	1	2	1	2
Hall Steps	2	1	1	1	2	2
Sleep Q 1-	2	2				
Meds 1-3	3	3	3	3	3	3
Headache N-3						
P/ Physical Activity 1-3			2			
P/ Mental Activity 1-3			1			



DiaCeph Monitoring By S Dolle On the Web: www.DiaCeph.com

DiaCeph Data Graphs March 8, 2010 (1st Day Onset Ltd Vision in 1 Eye)

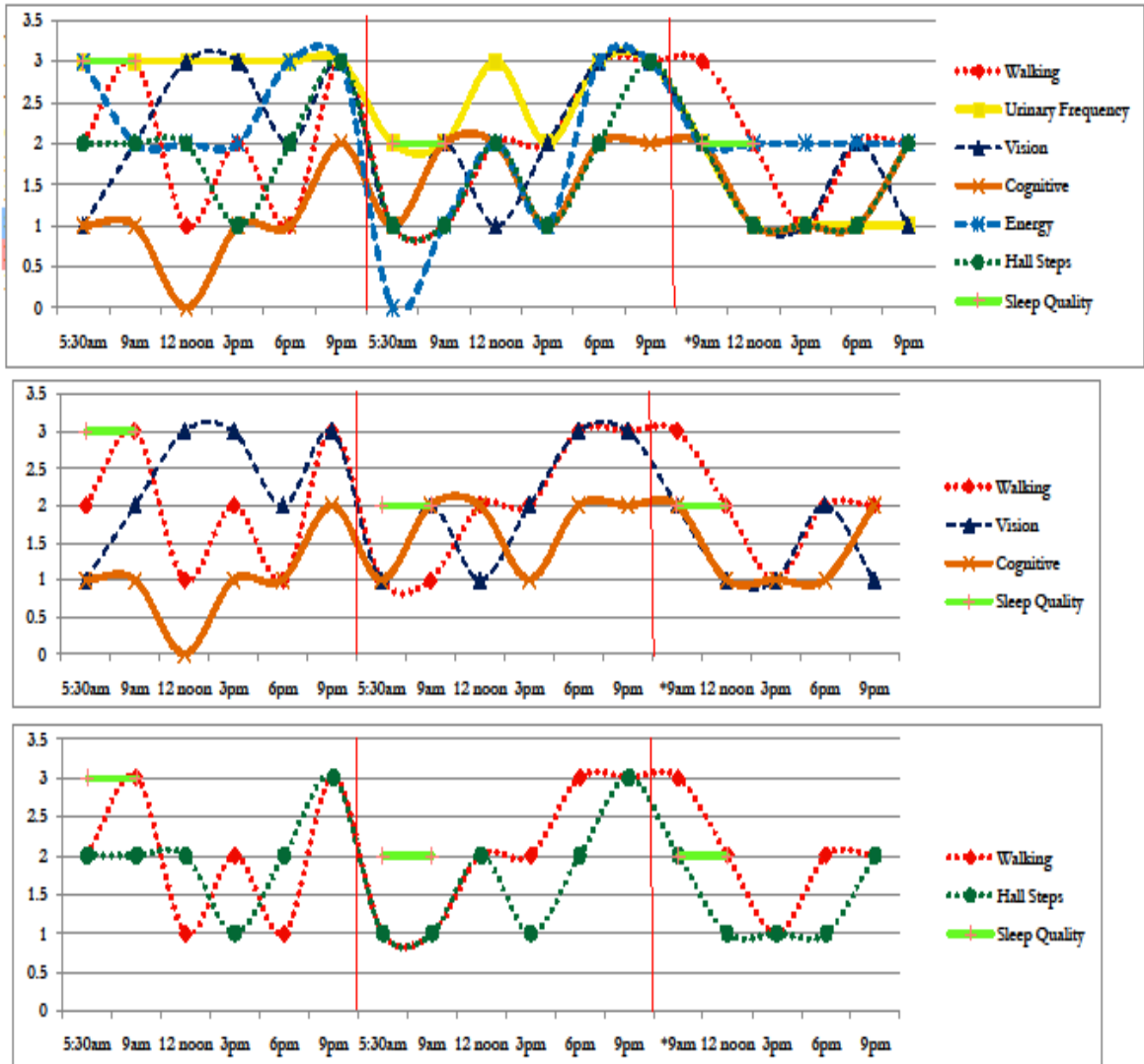
	5:30am	9am	12 noon	3pm	6pm	9pm
Walking N-	3	3	2	2	2	2
Urinary N-	3	3	2	2	2	2
Vision N-3	1	2	2	2	2	2
Cognitive 1	2	2	1	1	1	1
Energy N-	3	2	2	1	2	2
Hall Steps	2	1	0	1	1	1
Sleep Q 1-	3	3				
Meds 1-3	3	3	3	3	3	3
Headache N-3						
P/ Physical Activity 1-3			3			
P/ Mental Activity 1-3						



DiaCeph Monitoring by S Dolle On the Web: www.DiaCeph.com

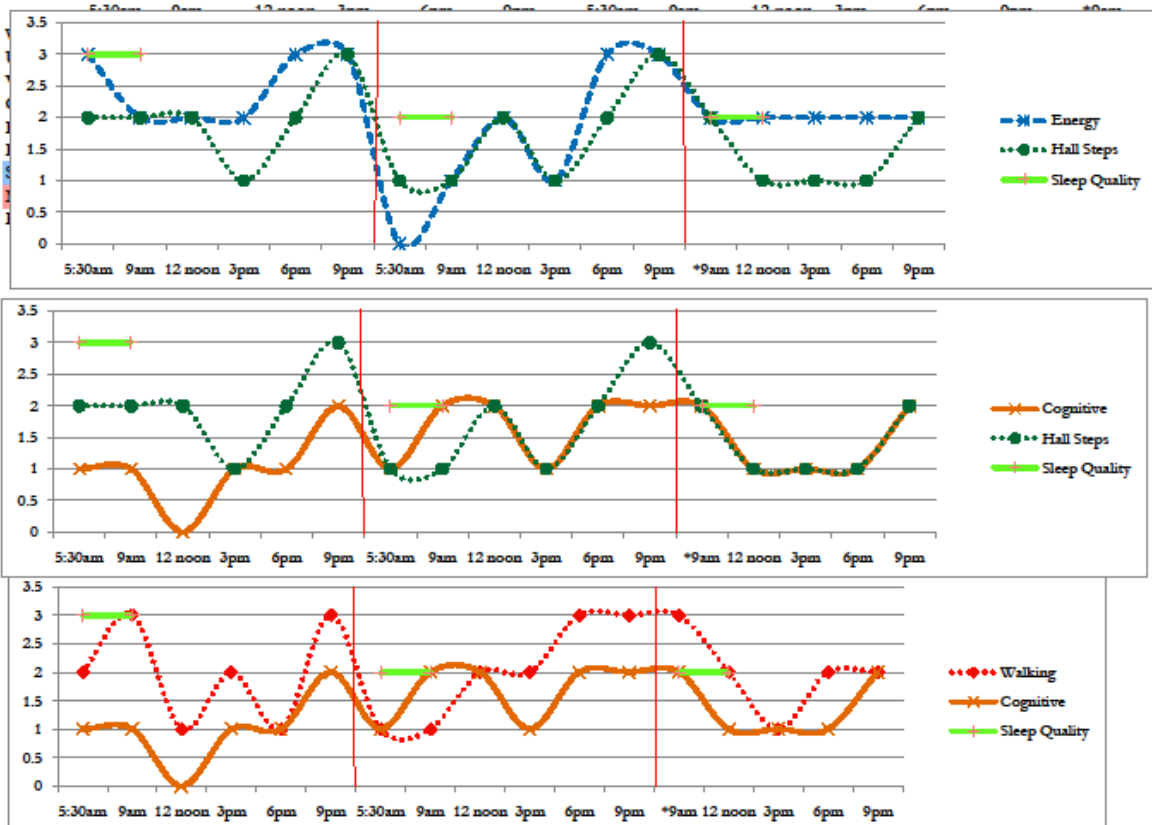
FIGURE 1.

DiaCeph Graph March 4, 5,6, 2010 All Markers: Walking v. Vision v. Hall Steps v. Cognitive



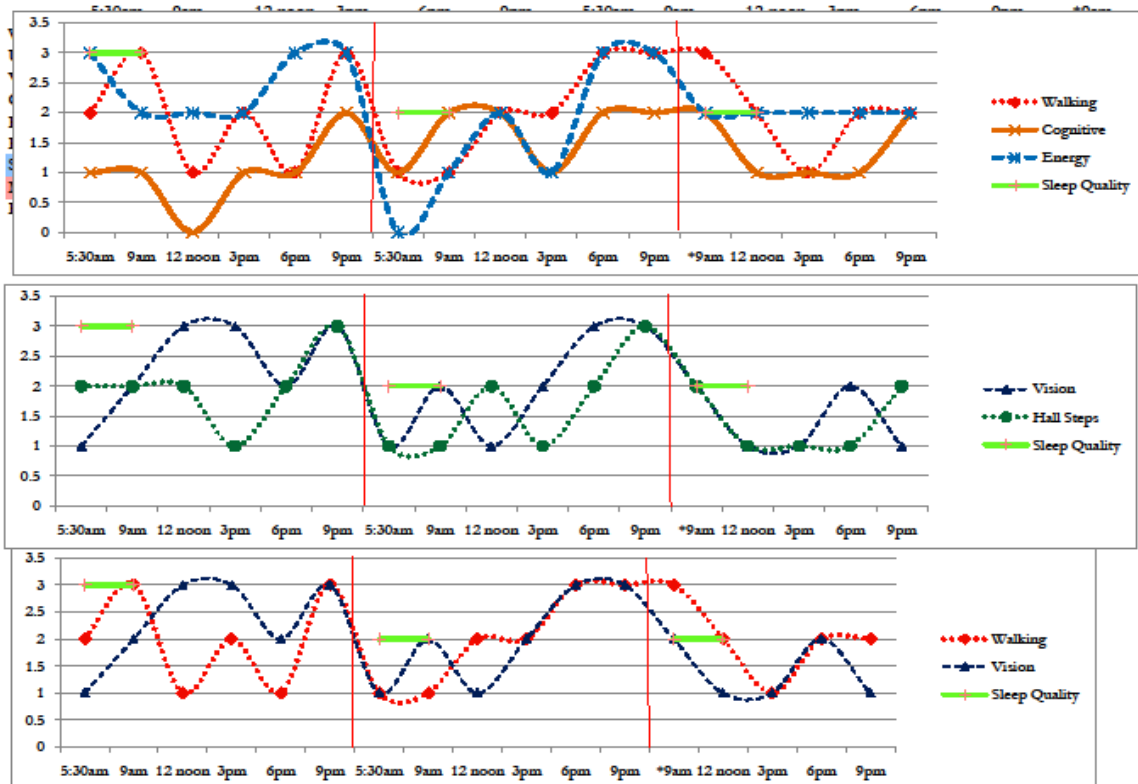
DiaCeph Monitoring by S Dolle On the Web: www.DiaCeph.com

FIGURE 2
DiaCeph Graph March 4, 5, 6, 2010 Markers: Energy v. Cognitive v. Walking

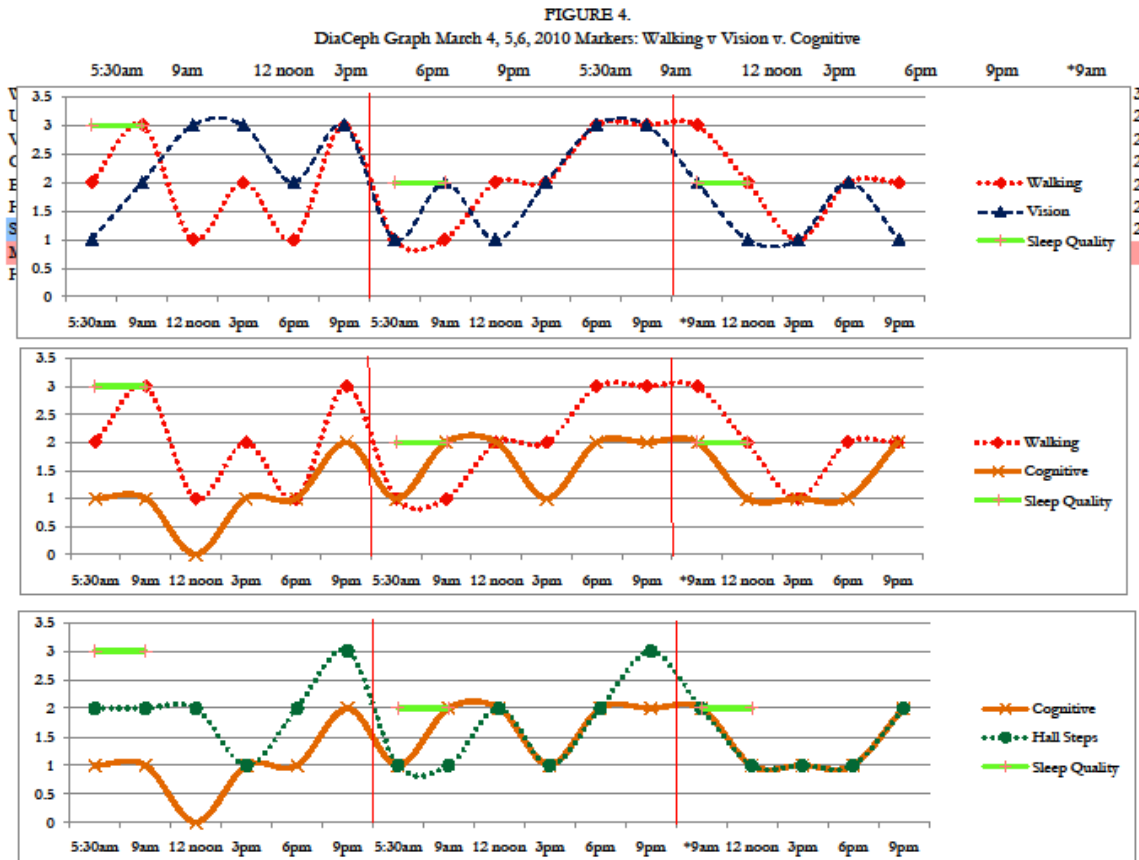


DiaCeph Monitoring by S Dolle On the Web: www.DiaCeph.com

FIGURE 3
 DiaCeph Graph March 4, 5, 6, 2010 Markers: Cognitive v. Energy, Walking v. Vision



DiaCeph Monitoring by S Dolle On the Web: www.DiaCeph.com



DiaCeph Monitoring by S Dolle On the Web: www.DiaCeph.com

Figures 1-4 indicate his Walking curve pares closely with his Hall Steps curve, with the Walking curve slightly more sensitive to subtle changes (Figures 1. and 3.). **** Note: data points and curves higher up and away from “0” on the vertical axis (near the 3.5 line) represent abnormal findings. Points nearer to the “0” point on the vertical line represent lesser complaints, more normal findings.**

Of his markers, perhaps the most telling is how well his Cognitive curve fits to his Walking and Hall Steps curves, and how they rise and worsen in the evening. The rise and fall of his Cognitive curve also mirrors his Walking and Hall Steps curves, which is consistent with NPH. However, the fluctuations in his Cognitive curves are less dramatic. This would be due to either test methodology, or that his cognitive changes are unrelated to NPH. His surgeon noted on his admission record of 11/30/09 that he was complaining of heaviness in his legs more in the evening, but that it had improved in the daytime. This would seem related to CSF outflow and NPH, likely “inadequate” CSF clearance. His surgeon also noted “orthostatic intolerance,”

which may well be the loopyness he is reporting. The ongoing heaviness in his legs is likely the elevated Walking and Hall Steps DiaCeph data seen later in the day and evening. We need additional monitoring to identify his “loopyness” in from data.

His neurocognitive assessment, as part of his in-hospital CSF drainage of 3/13/09, indicated his Cognitive complaints were mild and seemed unrelated to NPH. My personal observation was that his cognitive difficulties seem more like dementia. Short term memory (30 sec to 5 minutes) seems in-tact, with some difficulties in mid-term memory and recall of day to day details. This could still be related to NPH with mild shunt mis-match per his abnormal walking scores and loopyness. I used a 5 item TV station recall Cognitive test. He informed me the test seemed too easy and that he was too comfortable with it at home, as opposed to his being put on the spot in the physician’s office. So I changed his Cognitive test to a simple observation by his wife/assistant of his memory status. I would like to see how this Cognitive finding pares with his Walking and Target scores.

His Vision curves (prior to losing sight in his left eye) do not pare as closely with the rise and fall of his Walking and Hall Steps scores. On March 4, he reported his Vision marker mid-day as rising to severe (level 3), while his Walking and Hall Steps scores were mild (level 1). On March 7, his Vision improved to mild, while his Walking and Hall Steps scores moderated between mild and moderate.

On March 15 while in Newport Beach, his Vision was so impaired he required step by step assistance to move about his hotel room. At 5:30pm, as we headed to the hotel lobby, I observed him Walk without any shuffle, sway, or hesitation down a straight hallway arm in arm with his wife. When asked if he could walk like this prior to his April 2009 shunt placement, both he and his wife responded “no.” His Vision was also better then. He was also much less bothered by Urinary urgency.

On March 15-17, I observed him having poor balance and gait episodes after breakfast and mid-day, described as “loopy” when getting up from his seat and attempting to walk. On March 16, he was unable to stand steady with feet together (in a corner) and unable to stand heel to toe. He had a pronounced shuffle as he walked with me arm in arm.

These loopy and walking complaints I suspect are due to either “fluctuations” in intracranial pressure and NPH, or elevated blood pressure and heart rate. The episodes seem to pare his abnormal Walking and Hall Steps and Energy curves. The markers are also worse later in the day and evening. It is reasonable to expect that his NPH could impact his energy. He may also have a stamina issue. His blood pressure and heart rate were reported to be 162/100 and 105 by Dr. W. on 1/7/10, yet were 138/77 and 101 on 1/4/10. Dr. S. described his blood pressure and nystagmus findings on 11/30/09 as “orthostatic

intolerance.” He takes a stimulant anti-depressant prescription, Tenuate Dospan. It is possible the loopy and balance episodes are related to blood pressure and stamina. He reports being loopy after exercise. I asked him if he could lower his dosage of Tenuate. On 3/25/10, I was informed he had discontinued it all together. But he continues to experience loopy episodes, notably after a long walk. In lieu of this, I added a simple finger to Target circle (vestibular) test to be done 5 times a day.

His poor Sleep Quality seems to pare his Urinary urgency complaints as seen on curves in Figure 1., and pare less with his Vision, Cognitive, and Walking scores (Figures 1, 2, 3, and 4).

With a limited number of days of monitoring, his DiaCeph results seem to indicate intermittent exacerbation of his gait and walking complaints, likely due to NPH and suboptimal CSF clearance and shunt performance, but elevated blood pressure and heart rate as a cause cannot be ruled out. It is difficult to state with any degree of certainty (with the limited monitoring days), whether his suboptimal outcome is due to overdrainage, or underdrainage. His history would indicate the latter. He has a double-ASD shunt system that could lend itself to upright underdrainage. As his Strata valve was lowered, he did experience improvement in gait and walking complaints. It is presently set at 1.0. A trial period of 3-10 days at the 0.5 is a possibility. I would suggest additional monitoring to best understand his complaints, and avoid further complication and guesswork.

This monitoring should include:

1. Seven (7) more days of monitoring using the 4th Version DiaCeph Form, with Blood Pressure, HR, and Target circle monitoring.
2. Activity monitoring of loopy episodes, after exercise, and after spending a portion of the day in a supine posture (i.e. on the couch).

Impression:

1. Improving but unresolved walking and gait complaints, confirmed by treating physicians, by my own observations, and in a limited number of days of DiaCeph monitoring. This appears related to NPH, inappropriate CSF clearance, and sub-optimal shunting. His reported heaviness in his legs later in the day and evening seems to fit his abnormal Walking, Hall Steps, and Cognitive DiaCeph scores, consistent with NPH and undershunting. Lowering of his Strata setting and/or revision of his double ASD shunt system might bring some relief in his complaints.

2. Orthostatic changes presenting as dizziness and loopyness likely due to age, blindness and physical inactivity, anxiety, shunt drainage, and the number of reoperations/shunt adjustments in a relatively short period of time. This is likely the pattern seen in his improving gait scores, not as much in the TUG scores. It would appear his anxiety is being fueled by his complaints not having been resolved thus far, and is his reason for contacting me. I feel integrative medicine therapies and exercise can help with these complaints.

3. Lowering his Strata valve at this juncture also seems indicated. But it should be weighed against his ongoing anxiety and orthostatic challenges. Further DiaCeph monitoring would help to minimize the guesswork and exacerbation of his status.

4. Possible exacerbation of orthostatic complaints from the use of antidepressant medications (amphetamines), and Flomax.

5. Mild cognitive changes per my neuropsych exam and in-person assessment possibly due to NPH, though more likely related to dementia in view of the vascular changes seen on his CT and MRI brain scans. His 3/13/09 in-hospital CSF drainage trial presents some confusion as to when his baseline cognitive score was obtained during the drainage, and the accuracy of his cognitive and dementia data. Limited number of days of DiaCeph monitoring did confirm that his cognitive changes pare with his walking complaints, more consistent with NPH. It is unclear at this juncture how much of his cognitive complaints might abate if he were more optimally shunted.

6. Neuromuscular changes and reduced mobility in his neck, likely due to age and sports and injury history, which I did not evaluate. But it would seem to be adding to his physical inactivity, and fueling his orthostatic challenges.

7. This patient is a wonderfully intelligent, cooperative, and talented 70 year old man, who should respond well to shunting and most therapies. As with any surgical or therapeutic intervention, care should be taken so as to not overwhelm the patient with intervention(s). I believe this is what occurred with his bout of confusion following his 11/6/09 ETV and shunt revision. Given his eagerness to cooperate, and his present orthostatic challenges, I believe integrative therapies like acupuncture, Tai Chi, and meditation/ visualization, as well as a schedule of physical and social activities, may help his outcome.

Recommendations:

1. Continue with DiaCeph monitoring as described.

2. Continue treatment for his failed eye lens and retinitis pigmentosa.

3. Pursue integrative medicine therapies and physical exercise for orthostatic complaints.

4. Better moderation of antidepressant, amphetamine, and Flomax medications. I am informed he has discontinued the Tenuate medication.

5. Increased integration in social activities and personal interests.

6. Physical therapy and home exercises to improve mobility in his neck, and complaints in his shoulders and knee.

7. Discontinue fluids two hours prior to bedtime to avoid awaking at night.

8. Lower his Strata setting to 0.5 if/when indicated by additional monitoring.

9. Meet with a nutritionist to improve dietary intake of animal fats (prostate health), sugars, and caffeine.

10. Daily vitamins, including, saw palmetto.

11. Re-evaluation of his cognitive complaints at the appropriate time.

12. If further adjustment of his Strata valve and exercise/integrative medicine therapy does not provide relief, I suggest a revision of his double ASD shunt system to a Codman Hakim valve with or w/o Shunt Assistant, a Strata NSC with or w/o Shunt Assistant, or a Diamond Valve.

Attached, please find his DiaCeph/Excel Data Graphs from March 4, 2010 to March 15, 2010, and Comparison Graphs of March 4-6 as Figures 1-4.

Per instructions from this patient, a copy of this report and a summary letter were mailed to his Johns Hopkins Medical Center physicians.

I will append this report with a letter when new DiaCeph data is made available.

By:

Stephen M. Dolle

Inventor, DiaCeph Test for Hydrocephalus

Neuroscientist, Medical Consultant & Patient Advocate